# FORGIVENESS THROUGH THE DIALOGICAL SELF: A QUALITATIVE TRACK OF SELF-IDENTITY RECONSTRUCTION AMONG SURVIVING HIV-POSITIVE SPOUSES IN GWANDA SOUTH CONSTITUENCY.

by

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**DECLARATION**

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I declare that the above thesis is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the thesis to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

**Signature** ..... **Date** 30/12/2019

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**Dedication**

I lovingly dedicate this thesis to my loving wife, who supported me each step of the way and my wonderful children, to the surviving HIV-positive spouses for their inspiration, encouragement and stamina to face the eventualities of life with zeal, enthusiasm and fear of God.

**Abstract**

The purpose of this study was to explore the nature of changes that take place in surviving HIV-positive spouses' explanations of themselves in relation to their acquired positive status, and in relation to the role that forgiveness may play, all through Hermans' theory of dialogical self in the self-identity reconstruction process. The interpretive qualitative paradigm was used, along with a phenomenological research design. Research was carried out in a rural area of Gwanda South Constituency in Zimbabwe. Homogenous purposive sampling was used to select five HIV-positive widows and five HIV-positive widowers. In-depth, semi-structured interviews were used and thematic, narrative and interpretive phenomenological analyses were employed to analyse the data. The results showed that the surviving HIV-positive spouses faced a plethora of challenges following the deaths of their partners. Identified key relations to the reconstruction of a new self were found to be: a good knowledge of HIV; being at peace with the past self; forgiveness of self; and reconciliation with what has happened. These were found to be good ingredients for quick recovery and self-identity reconstruction. Significant others play an important role in self-identity reconstruction as they offer an environment that is supportive of HIV disclosure, thereby reducing the occurrence of stigma and discrimination. The study recommends that HIV activists and all education systems that are involved in the HIV campaigns in Gwanda South Constituency incorporate teachings about and awareness of forgiveness, reconciliation, stigma and discrimination at all levels of their education efforts and campaigns.

**Key terms:** Forgiveness; reconciliation; dialogical self; self-identity; reconstruction; self-identity-reconstruction; surviving HIV-positive-spouses; significant others; widowhood; stigma and discrimination; spoiled-self:

**(Abstract in IsiZulu)**

## Iqoqo

**Ukuzixolela ngokukhuluma nawe siqu sakho: Indlela eqhutshwa ngezingxoxo yokwakha isithunzi sakho kabusha kwizithandani eziphilayo ezinegciwane leSandulelangculazi (*HIV*) kwiSigodi saseNingizimu yaseGwanda**

Inhloso yalesisifundo socwaningo kwakukuphenya uhlobo lwezinguquko ezenzekayo kwizithandani eziphilayo ezinegciwane leSandulelangculazi (*HIV*), uphenyo lwalugxile kwizincazelo ezazenziwa yibolaba bantu ngezimpilo zabo mayelana nesimo esintsha sokuphila naleligciwane, kanti futhi mayelana nendima engadlalwa wukuzixolela, ngokohlelo lomqondo/lwethiyorika Hermans yokuxoxisana nawe siqu sakho ohlelweni lokwakha kabusha isithunzi sakho wena qobolwakho. Uhlelolwe-*interpretive qualitative paradigm* lwalusetshenziswa, kanye nohlelo locwaningo oluphenyisisayo. Ucwaningo lwaluqhutshwa endaweni yasemakhaya eSigodini saseGwanda engaseNingizimu eZimbabwe. Indlela enenhloso yesampuli yasetshenziswa (h*omogenous sampling*) ukukhetha abafelokazi abahlanu abanegciwane leSandulelangculazi (*HIV positive*) kanye nabafelwa abahlanu abanegciwane leSandulelangculazi (*HIV positive).* Uhlelo lwenhlolombono olujulile, olumbaxambili lwasetshenziswa kanti futhi indlela yokuhlaziya ndikimba, ingxoxo kanye nokuchazwa kwefenomenoloji isetshenzisiwe ngesikhathi kuhlaziywa idatha. Imiphumela ikhombise ukuthi izithandani eziphila ngegciwane lesandulelangculazi zibhekene nengwadla yezinselelo ngemuva kokushona kwezinqandamathe zabo. Izimpawu ezitholakele ezimayelana nokwakha kabusha isithunzi sakho wena ngokwakho yilezi ezilandelayo: ukubanolwazinge-HIV; ukudlulisa engqondweni lokho okwenzeka esikhathini esedlule, ukuzixolela wena siqu sakho kanye nokwenza ukuthula nalokho okwenzekile. Lezizimpawu yizo ezatholakala ukuthi zilungele ukuba yizinongo ezisheshayo zokuzelapha kanye nokwakha kabusha isithunzi sakho. Ezinye izimpawu zidlala indima esemqoka kuhlelo lokwakha isithunzi sakho kabusha njengoba zendlala isimo sokusekela labo abanegciwane lesandulelangculazi ngokuthi baveze isimo sabo se-*HIV,* ngalokho-ke, banciphisa izinga lesithombe esibi kanye nokucwaswa. Ngakho-ke, isifundo socwaningo sincoma ukuthi abashoshozeli besandulelangculazi (*HIV*) kanye nazo zonke izinhlelo zezemfundo ezibanda kanye kakwimikhankaso ye-HIV kubantu abahlala esiGodini esingaseNingizimu yaseGwanda ukuba balandela izifundiso ezimayelana nalokhu kanye nokwexwayiswa ngalokhu kuxolela, ngokuxolelana, isithombe esibi kanye nokucwasana. Kuwo wonke amazinga abo ezemfundo kanye nemikhankaso yabo.

**Amagama asemqoka:** Ukuzixolela, ukubuyisana, ukukhulumisana nawe siqu sakho, ukwakha isithunzi sakho kabusha; izithandani eziphila negciwane eliyisandulelangculazi, abanye abasemqoka, isimo sobufelokazi, igama elibi kanye nokucwasana; ukuphoqa wena ngokwakho.

**(Abstract in IsiNdebele)**

**Ikulumo ngobufitjhazana**

**Ukuzicolela ngokukhulumisana nawesiqu sakho: Indlela eragwango kucocisana nawengokwakhona kuvuselelwa ngobutjha isithunzi sakho hlanganane enthandani eziphila ngengogwana ye-*HIV*esiGodini esise Sewula yeGwanda**

Ihloso yalelirhubhululo kwakukuphenyisisa ubunjalo bamatjhuguluko enzekakubantu abaphilange-HIV, lokhana bazihlathulula bona ngokwabo malungana nobujamo obutjhabentumbantonga abazithole sebakibo, begodumalunganane ndima engadlalwakucolelana, ngokusebenzisa umqondoka Herman wokukhulumisana nawengokwakho ehlelweni lokuvuselelwa ngobutjhakwesithunzi sakho. Ihlelo le- *interpretive qualitative paradigm* lasetjenziswa, ngokukhambisana nehlelo lerhubhululo eliphenyisisako. Irhubhululo lenziwa endaweni yemakhaya eseSewula yeGwanda eZimbabwe. Ihlelo elinehloso elisebenzisa isampuli efanako yobulili obubilili setjenziswe ukukhetha abafelokazi abahlanu abane-*HIV* kanye nabafelwa abahlanu abane-*HIV*. Amahlelo azi inqephu ezimbili wehlolombono edephileko asetjenziswe kanti namahlelo wokutsenga ummongo, ikulumo kanye nokuhlathululwa kwefenomenoloji kusetjenzisiwe ukuhlathululula idatha. Imiphumela ikhombise ukuthi iinthandani eziphila nengogwana ye-HIV zaziqalene nenyanda ye entjhijilo ngemuva kokuhlongakala kwabalinganibabo. Amatshwayo atholiweko aqakathekileko amalunga nanokwakhiwa ngobutjha kwesithombe sakho wena siqu sakho atholakele: kukuhle ukuba nelwazi nge-HIV; kukuhle ukucolela ubunjalo bakho siqu sakho besikhathi esedlulileko; ukuzicolela wena siqu sakho kanye nokwenza umoya wokubuyisanana lokho okwenzekako. Lamatshwayo atholakele azi inthako ezelapha msinyana kanye nokwakha ngobutjha isithunzi sakho. Okhunye okubalulekileko kubabantu abadlala indima eqakathekileko ekwakhiweni ngobutjha kwesithunzi sakho njengombana baletha ibhoduluko elisekela lokhu nawuveza ubujamo bakho be-HIV, ngalokho baphungula izinga lesithombe esimbi kanye nokukhethululwa. Irhubhululo liqunta bona abatjhotjhozeli be-HIV kanye nawo woke amahlelo abandakanye kakokumajima we-HIVendaweni yeGwanda eseSewula balandela iimfundiso ezimalungana nalokho begodumalungana nokuyeleliswa ngokuqakatheka kokubuyisana; kwesithombe esimbi kanye nokukhethululwa kiwo woke amazinga wemizamo yabo yefundo kanye nemajimeni wabo.

**Amagama aqakathekileko: Ukucolelana, ukubuyisana; ukukhulumisana nawesiqu sakho; wena siqu sakho; ukwakha ngobutjha; ukwakha ngobutjha isithunzi sakho; iinthandani eziphila ngengogwana ye-HIV; abanye abaqakathekileko; ubujamo bobufelokazi, isithombe esimbi kanye nokukhethululwa; ukuziphoqa wena ngokwakho.** :

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# CHAPTER ONE
# INTRODUCTION

## 1.1 Background to the study

Understanding ourselves and our place in the world is usually a lifelong struggle for most of us. This struggle is even more challenging when one experiences a life changing event, such as the death of a spouse and being HIV positive. Such unplanned for events alter forever the ways that people experience and construct meaning in their lives. This research aims to explore the process of reconstructing one's self following the death of a spouse and being HIV positive, and the role forgiveness plays through the dialogical self in this process.

Traditionally, the development of theories and concepts of the self has come from distinctly separate psychological or sociological perspectives. In psychological literature, Kowalski and Leary (2004) observed that typically the self has been studied in clinical laboratories; separated from the experiences, culture and relationships in which it may develop and be expressed. From a more sociological perspective, the self is viewed as the result and expression of the relationships between the person, society and role performance. Kowalski and Leary (2004) suggest that there has been a narrowing of the gap between sociological and psychological views, however, with a dynamic, multifaceted, contextual-relational view of the self emerging. Contemporary social-psychologists refer to the multiplicity of identity as encompassing one's social roles as well as personal characteristics. In their review of the psychological literature on the self, Leary and Tangney (2012) suggest that one of the stumbling blocks to linking the self to behaviour has been the view of the self-concept as stable or generalised. Their solution is to view the self-concept as a multifaceted phenomenon that is, as a set or collection of images, schemas, conceptions, prototypes, theories, goals or tasks. Self-representations are activated, according to Leary and Tangney (2012), depending on the prevailing social circumstances and the individual's motivational state; motives relating to self-enhancement, and self-consistency. Self-concepts are cognitive structures that can include content (being HIV positive), attitudes (how you feel about being HIV positive), or evaluative judgments (what you think and what others are saying about you being HIV positive) and used to make sense of the world, focus attention on one's goals, and protect one's sense of basic worth (Oyserman & Destin, 2010). Thus, the self is

the '*I*' that thinks and the'*me*' that contains those thoughts. One important part of this '*me*' involves mental concepts or ideas of who one is, was, and will become. These mental concepts are the content of self-concept and these get affected in the event of one being HIV positive.

Recoeur (1992) and Taylor (1989), both think that when referring to self-interpretations, the central question is one of the particularities of one's self-identity, and the answers are provided within culturally and socially mediated self-interpretations. This implies that the hermeneutic view of the self and narrative identity is located between an affirmation of a certain and indubitable '*I*' and a total rejection of that '*I*'. Further, it means that the person in question – the surviving HIV positive spouse – together with others, is both the interpreter and the interpreted. Recoeur (1992) holds that narrative identity mediates between two kinds of permanence in time, one based on voluntary efforts and the other on character. Narrative identity contains both concordance and discordance, both unity and plurality. The plurality in question can be both synchronous and diachronous. While Taylor (1989) focuses on the plurality and discordance on the level of strong evaluations, Recoeur (1992) deals with all kinds of discordance in the world of action.

Narrativity and self-interpretations in general, include dialectic of innovation and sedimentation. The implicit layers of one's habitual and characteristic orientations are moulded through explicit articulations in narrative and other forms. Because of the central role of strong evaluations in our identity, we can see that identity is not a mere description. To sum up, self-interpretations and narrative identity can be characterised as the mediation between all of the different extremes. Given the central role of temporality in human existence, it would not be an exaggeration to claim that narratives are central medium of self-interpretation. Our life is not just a continuum of separate events, but rather our past and our future always structure our present experiences and action.

As a social phenomenon, widowhood has been in existence as long as socially-regulated marriage. Ntozi (1997) observed that between birth and death of a person, marriage is one of the events perceived as important by society; it changes the personalities, the attitudes and life-style of men and women. Berman (2015) postulates that marriage is entered into with great hopes and expectations and becoming a widow or widower often interrupts this anticipated future. The death of a spouse is the most life-changing event that one is likely to experience. Berman (2015)

further postulates that while widowhood is often never anticipated, becoming a widow/widower as a result of HIV is perceived as a failed marital life, and therefore, it has serious repercussions on the individuals, family and the community. A life-changing event may not necessarily be the most devastating event: there is no hierarchy or calculus of loss, and the death of a child or parent may awaken in some people the most intense grief. Berman (2015, p. 1) says *".. most researchers believe that the death of a spouse, the person with whom one has lived for a lifetime and whom one knows (and is known by) better than anyone else, is the most life-altering event. No matter how independent one is, living with a beloved spouse for many decades is like living with the better part of one's self. Life without that other becomes unimaginable. When the unimaginable occurs, one may not wish to remain alive, that's why widowhood is so harrowing and destabilising."* Many researches (Ntozi, 1997; Matovu, 2010) and observations have shown the negative results of widowhood. Upon being widowed, individuals may experience a whole range of emotions including chaos, anger, resentment, denial and disbelief. This may be followed by intense grief, and a search for the lost person, and that usually happens in every society. Eventual acceptance of the death of one's partner can lead to depression. To successfully survive, the widow or widower has to recognize her/his life in an entirely new and unexpected way (Bernardes, 1997, p. 104). As a whole, widowhood is almost always a tragedy. With these challenges accompanying widowhood in general, it becomes an added burden when the surviving spouse is HIV positive and the other partner died of HIV related illnesses.

Much of our accepting of becoming and being widowed comes from qualitative research in which in-depth interviews and narratives reveal the process and dynamics of this major life transition. An initial response to widowhood is a sense of lost identity (van den Hoonaard, 2010). Particular triggers, like having to fill out marital status on a form, or being introduced as someone's widow, or the sudden self-realisation of being a widow, start the course of action of acquiring a personal and social identity as a widow (van den Hoonaard, 2010). This process is described by an old widower: "I have to recreate my life, have to recreate my thinking" (Moore & Stratton, 2002, p. 87).

Losing a partner at an early age creates a plethora of problems as the surviving partner has to consider remarrying and sometimes looking after young children alone, (Doka, 2002; Kauffman, 2002). The loss of an intimate partner often occurs in the context of multiple losses due to HIV

within a closely knit community and issues such as stigma and discrimination become a worry to the surviving spouse, (Attig, 2000). Providing care to an ill spouse for a long time can lead to isolation of both partners. This may leave a newly widowed person poorly prepared for dealing with life alone. Nonetheless, most old persons make the transition to widowhood successfully. Grieving openly is often difficult for HIV positive people or for their loved ones because of the secrecy and stigma associated with HIV and experiencing pain alone or secretly often makes the pain worse.

Human beings appear to have an innate proclivity to reciprocate negative interpersonal behaviour with more negative behaviour. The tendency to retaliate or seek retribution after being victimised is deeply ingrained in the biological, psychological, and cultural levels of human nature (Yadav & Singh, 2017). People are motivated to respond to injuries and transgressions by committing further injuries and transgressions equivalent to those they have suffered. Victims tend to view transgressions as more painful and harmful than do perpetrators (Scobie & Scobie, 1998). Without being forgiven, that is, released from the consequences of what we have done, our capacity to act would be confined to a single deed from which we could never recover; we would remain the victims of its consequences forever (Black, 1998). Forgiveness is influenced also by the characteristics of transgressions and the contexts in which they occur. Generally, people have more difficulty forgiving offences that seem more intentional and severe and that have more negative consequences (McCullough et al., 2000). The extent to which an offender apologises and seeks forgiveness for a transgression also influences victim's likelihood of forgiving. Why do apologies facilitate forgiveness? By and large, the effects of apologies appear to be indirect. They appear to cause reductions in victims' negative affect towards their transgressors and increases in empathy for their transgressors. Victims also form more generous impressions of apologetic transgressors. Perhaps apologies and expressions of remorse allow the victim to distinguish the personhood of the transgressor from his/her negative behaviours, thereby restoring a more favourable impression and reducing negative interpersonal motivations. Here the self will be in disharmony, to forgive or not to forgive, that is forgiving the person who infected you with HIV or forgiving yourself for getting infected.

The facet of forgiveness can be conceptualised in two dimensions – forgiving and being forgiven. This conceptualisation suggests four separate areas of inquiry as observed by

McCullough, Pargament and Thoresen (2000, p. 38): (1) whether people forgive themselves for getting infected; (2) whether they forgive others—family, partners, caregivers, God, Divine being, or spiritual forces (for example, others who they believe have let them down, failed to protect them, led them into situations that resulted in infection, or caused them other misfortune); (3) whether others forgive them (for example, for being a burden, an embarrassment, or for having violated their trust); (4) whether God or spiritual forces forgive them.

People living and dying from HIV have spiritual and emotional as well as medical needs. They ask questions related to God and the soul, condemnation and forgiveness. HIV brings anxiety and despair, and issues of soulfulness, life, death, condemnation and forgiveness, eternity and salvation to the surface. The person living with HIV longs for soulfulness, life, death, forgiveness, salvation, eternity, consolation and acceptance that are provided by a caring community which graciously accepts and identifies with the person. The surviving HIV positive spouses who have been able to forgive others and let go of unproductive feelings of anger, bitterness, resentment, or disappointment will probably be able to seek and receive social support more effectively from others. Feeling forgiven is associated with feeling loved, connected with others in a positive way, and feeling higher in self-esteem (McCullough, Pargament & Thoresen, 2000). Forgiveness in this context would be hypothesised to be related to enhanced quality of life.

An issue of equal importance facing widowed spouses is the task of establishing a new identity. To lose a spouse is to lose something of one's self, many spouses experience seeing themselves as only half a person following the loss of their husband or wife (Kinderknecht & Hodges, 1990, p. 43). For women, one aspect of formulating a new identity is that of title because many women have been known as Mrs. Somebody. In re-organising her life, the widow must decide what her title will be. Another identity issue for both men and women involves their new role within the couple's old circle of friends. When the spouse who is now bereaved was part of a couple, this social network was probably comprised mostly of other couples. It can be painful to be with these friends now, and the bereaved spouse may wonder how he/she will fit in and feel comfortable as a single person in this social network. This situation becomes worse in a discriminatory society like a rural Zimbabwe where HIV is still shunned as an immoral disease.

Handling anger and other negative feelings is an important but difficult part of the grieving process. Bereaved spouses often struggle to hold on to the positive aspects of a relationship that they desperately miss. It is difficult for them to confront the fact that they are angry at their spouses for leaving them or that there were negative aspects of the marital relationship that they must let go of, not just positive aspects (Brabant et al., 1992). This difficulty is magnified by society's tendency to sanctify persons who have died, putting them on a pedestal (Lopata, 1979). Viewed from a constructivist perspective, grieving is a process of reconstructing a world of meaning that has been challenged by loss. Although most people successfully navigate bereavement and retain or return to pre-loss levels of functioning, Walque & Kline (2009) argue that a significant proportion of surviving HIV positive spouses struggle with protracted grief, and are unable to find meaning in the wake of an unsought transition. From a constructivist perspective, the loss of a loved one can challenge the validity of core beliefs and undermine the coherence of the self-narrative.

### 1.2 Problem statement

The death of a spouse in general has far-reaching effects on the surviving partner and it becomes worse if the surviving spouse is HIV positive. The surviving HIV positive spouse must cope, not only with emotional loss, but also with a sea of changes in daily routines and future plans inclusive of stigma. While the loss of one's spouse can be one of the most traumatic events in an adult's life, Walque & Kline (2009) argue that within a year or two, the surviving HIV negative spouse usually bounces back to earlier levels of physical and psychological health but the surviving HIV positive spouse would take longer to recover. Surviving HIV positive spouses can make a successful transition from the loss of a spouse back to a rewarding life by accepting and addressing their emotions, taking practical steps to secure their financial and physical health, and empowering themselves for the future.

As the HIV pandemic continues to wreak havoc in the Zimbabwean communities, there is a sizeable number of surviving HIV positive spouses that a difficult life out there in the rural Zimbabwe. When a partner succumbs to an HIV related illness, the surviving spouse has to find a way to continue with life. It has been observed that the surviving HIV positive spouses often find it difficult to remarry and live normal lives (Matovu, 2010). In a study on the role of widows

in heterosexual transmission of HIV in Zimbabwe, Lopman et al. (2009) found that owing to the need to engage in sexual activities following deaths of spouses, widows play a key role in the transmission of HIV. In some instances, it will be out of lack of knowledge and an authentic desire to lead a normal sexual life yet, in some cases, it will be wilful transmission of the virus to innocent partners. It is, therefore, clear that in as much as widows and widowers seek to live normal sexual lives, there is always a risk of the possibility of transmission of HIV between couples. Mutangadura (2000) contends that life after the death of a spouse due to HIV often changes as one has to adjust to the issues involving HIV and to live without a partner. On widowhood, Ntozi (1997, p. 125) states that, "life is characterised by grief, bereavement, rituals, forced marriages, harassment, rejection, loneliness, poverty and relative mortality." These plethora of problems double if the surviving spouse is HIV positive due stigma and discriminatory tendencies of rural Zimbabwean communities.

The high incidence of HIV and AIDS in Zimbabwe and other countries has led to a clamour for the criminalisation and imposition of harsh penalties on those who intentionally engage in activities that will lead to the transmission of HIV. This led to the creation of such an offence in Zimbabwe. This offence is provided for in section 79 of the Criminal Law (Codification and Reform) Act [*Chapter 9:23*]. The objective of this offence is to try to prevent the deliberate transmission of HIV.

**Intentional HIV transmission**

The heading for this offence is "Deliberate transmission of HIV". This is somewhat misleading. Although the offence can be committed if the accused actually infects the complainant, it can also be committed without proof of actual infection of the complainant by the accused. Where the accused realises that there is a real risk that he or she may be infected and he or she has sexual intercourse with another realising that there was a real risk or possibility of infection, he or she is guilty of the offence. This formulation does not require actual proof of infection.

Where the State is alleging that the accused actually infected the complainant, it would have to establish that the complainant did not already have HIV before the accused allegedly infected him or her. If, for instance, the accused rapes and infects a young girl who was a virgin, it will be clear that it was the accused who infected her unless, of course, her mother infected her when she

gave birth to her. But with adults it may be difficult to establish which of the two partners was infected first as this cannot be determined by medical evidence.

In cases involving sexual intercourse the offence is committed in the two situations below:

1. The accused, who actually knows that he or she is infected with HIV, has sexual intercourse with another person knowing that this will infect that person with HIV and the complainant does not know that the accused has HIV when they have sexual relations.
2. The accused, who realises that there is a real risk or possibility that he or she is infected with HIV, has sexual intercourse with another person realising the real risk or possibility that the other person will be infected with HIV and the complainant does not know that the accused has HIV when they have sexual relations.

It is explicitly provided that this offence is committed by an accused "whether or not that he or she is married to the other person."

It is a defence for the accused to prove (on a balance of probabilities) that the person with whom he or she had sexual relations knew that the accused was infected with HIV or consented to have sexual relations with him or her appreciating that the nature of HIV and the possibility of becoming infected with it. This defence requires the accused to prove not only consent to sexual intercourse but also that the complainant appreciated the nature of HIV and that that the sexual intercourse could lead to that person being infected.

In most cases HIV transmission takes place through sexual intercourse although there are other ways of transmission, such as deliberately plunging into a victim a syringe known to have been contaminated with HIV.

The challenge to the constitutionality of this offence is focused on the species of this offence requiring only that when the accused has sexual intercourse with another person the accused realised the real risk or possibility that he or she was infected with HIV and that there was a real risk that the other person will be infected with HIV. The rural people might not even know about

the legal routes to follow and even if they know, the legal procedures and proceedings are very expensive and out of reach for a common person in Zimbabwe.

It is clear from these observations that there are a plethora of challenges faced by the surviving HIV positive spouses. HIV in the marriage is usually brought in by one of the partners; hence its coming brings the issue of mistrust. Betrayal is the trust bridge that has been damaged or destroyed. The ensuing gap is huge and the challenges ahead are not easy. There are no shortcuts; it simply takes time to heal, to earn the trust that was lost and to reconstruct the bridge. This is the journey travelled by the surviving HIV positive spouses as they reconstruct their self-identity by means of forgiveness through the dialogical self.

### 1.3 Aim and objectives

The study aimed at broadly exploring the nature of changes that take place in the surviving HIV positive spouses' explanatory of their self in relation to their acquired HIV positive status, and in relation to the role that forgiveness may play through the dialogical self in the self-identity reconstruction process. Likewise, through the research, I aimed at tracing the adjustment process of widows and widowers in carving a new life.

I further aimed at unearthing the feelings of the surviving HIV positive spouses as they travel the journey of self-identity reconstruction by means of forgiveness through the dialogical self. In an effort to achieve the above-mentioned aim, the following objectives are distinguished:

1.3.1 To explore the ways in which surviving HIV positive spouses' make meaning of their current selves in relation to their acquired HIV positive status;

1.3.2 To get an understanding of the nature of the relationship that exist between the surviving HIV positive spouses with their significant others; and

1.3.3 To understand how the surviving HIV positive spouses make meaning of their past selves, their current, and possible future selves.

### 1.4 Research questions

The study was predicated on the following research questions:

1.4.1 How do the surviving HIV positive spouses' make meaning of their current selves in relation to their acquired HIV positive status?

1.4.2 What is the nature of the relationship between the surviving HIV positive spouses and their significant others?

1.4.3 How do the surviving HIV positive spouses make meaning of their past selves, their current and possible future selves?

**1.5 Justification of the study**

My research interest emerged from a deep concern regarding how there seems not to be enough attention paid to the surviving HIV positive spouses. The issue of HIV prevalence continues to be the main cause for concern for many societies in general, Zimbabwe in particular. Coupled with HIV related illnesses are numerous HIV related deaths experienced daily. In a study on widows and widowers, Ntozi (1997), found that in Uganda many widowers who were HIV positive and knew their status went on to remarry following the deaths of their spouses and this resulted in the infection of new sexual partners. Although the current data show that the global HIV epidemic is stabilising, statistics still report a high level of infection and progress is uneven in many countries (UNAIDS, 2014). Sub-Saharan Africa remains the most affected region in the world and it is home to almost 67% of all people living with HIV (PLWHA) (UNAIDS, 2014).

In Zimbabwe, the prevalence of HIV among men and women in different areas is quite high. The higher HIV prevalence in small towns, farming estates, mines and rural areas could be attributed to ignorance and lifestyles that promote the spread of HIV. The Ministry of Health and Child Welfare and National AIDS Council (2014) states that in 2013, HIV prevalence was 28% in urban areas and 21% in rural areas. Therefore, despite access to information on preventive measures, urban areas had higher HIV prevalence than rural areas. The Ministry of Health and Child Welfare and National AIDS Council (2014) further noted that as at 2014, 25% of the whole adult population aged between 15 and 49 was infected by HIV, and that the majority of the infected people are not even aware of their HIV status. ZNSA (2016) also noted that Zimbabwe has one of the highest HIV prevalence in sub-Saharan Africa at 12.7%, with 1.3 million people living with HIV in 2018. The HIV epidemic in Zimbabwe is generalised and is largely driven by unprotected heterosexual sex. Heterosexual people in stable unions (marriages)

account for around 55% of all new HIV infections. This shows that among the adults, marriage is high risk of acquiring HIV especially among the heterosexual partners.

People living with HIV (PLWHA) face not only medical problems, but also social problems associated with the disease. One of the barriers to reaching those who are at risk or infected with HIV is stigma (Greeff, 2008). Stigma enhances secrecy and denial, which are also the catalysts for HIV transmission (Rankin et al., 2005). Although the reaction to PLWHA varies, with some PLWHA receiving support which positively affects them, HIV stigma negatively affects seeking HIV testing, seeking care after diagnosis, quality of care given to HIV patients, and finally the negative perception and treatment of PLWHA by their communities and families, including partners (Herek & Glunt, 2012). HIV isolates people from the community and affects the overall quality of life of HIV patients (Miller & Rubin, 2007).

**Stigma and Discrimination**

Stigma and discrimination towards people living with HIV in Zimbabwe remains rife, with one study finding that 65% of living with HIV had experienced some form of discrimination due to their HIV status, (ZNNPLH, 2014). Survey data from 2015 found 22% of women and 20% of men who were aware of HIV had discriminatory attitudes towards people living with HIV. Around 6% of women and 9% of men did not think children living with HIV should be allowed to attend school with children who are HIV negative. Additionally, 19% of women and 16% of men would not buy fresh vegetables from a shopkeeper with HIV, (ZNSA, 2016). The effects of stigma are far reaching. Around 40% of sex workers questioned said they avoid healthcare due to stigma and discrimination and around 6% of people living with HIV report being denied some form of healthcare due to their positive status, (ZNSA, 2016).

Stigma may be internalised and experienced as shame or guilt, or externalised as discrimination. It may lead to reduced self-confidence, loss of motivation, withdrawal from social contact, avoidance of work-and-health-based interactions, and the abandonment of planning for the future. Stigma and discrimination have profound implications for HIV prevention, treatment, care and support. It reduces an individual's willingness to be tested for HIV, to disclose their HIV status, to practice safe sex and to access health care. Stigma impedes the efforts of services

to reach people most in need of prevention, treatment and care. It impacts an individual's capacity to acknowledge and manage their own HIV infection, affecting their physical and psychological well-being and quality of life (Goldin, 2009). Moreover, the social acceptability of stigma and discrimination affects governments' willingness to take the measures required to minimise HIV transmission and to guarantee the protection of human rights.

Stigma is based on socially defined norms of behaviour, moral judgments and fear. Although socially constructed, it frequently has tremendous personal effects (Goldin, 2009). It takes time to adjust to being HIV positive. The reality is that people with HIV need to be selective about disclosing, and they need to be selective about who they tell and when they tell them. This process of selection often involves uncertainty and can sometimes be an agonising experience. Wanting to tell family members, employers, fellow employees, and friends is very natural. However, disclosure is complex and may create challenges for the person who chooses to disclose. Over the past twenty years of the HIV epidemic, there have been some significant improvements in the general public's awareness about HIV and the understanding of HIV issues. Unfortunately, there is still stigma attached to the whole subject of HIV and to those who have it. While there may be better understanding and wider acceptance than in the past, unsympathetic and prejudicial reactions are still not uncommon in some families, in the workplace, and in social situations. In the face of life-threatening illness and losses, a person's coping capability is heavily taxed and challenged (Gilmore & Somerville, 2000). In a collective-oriented culture, such as Zimbabwe, individuals are expected to exercise self-restraint in containing psychological distresses and maintaining full function in productive roles. The association with specific sexual behaviour that is considered socially unacceptable by many people contributes to the stigma associated with HIV infection (Wood & Lambert, 2008). HIV provides an example of how illness, despite the biological characteristics of its signs and symptoms, always carries a second reality expressed in cultural images and metaphors. Chimwaza & Watkins (2004) argue that even when Anti-Retroviral Therapy (ART) is available and the outcome of HIV not always fatal, the link between HIV and bad (sexual) behaviour is still a concern for PLWHA because of shame and embarrassment.

Central to the surviving HIV positive spouses are questions of self and identity. Concepts of the self are inextricably intertwined in our past and current experiences. As Taylor (1989) argues

that what I am as a self, my identity, is essentially defined by the way things have significance for me. My self-interpretation can only be defined in relation to other people, an inter-change of speakers. I cannot be a self on my own, but only in relation to certain interlocutors who are crucial to my language of self-understanding. In this sense, the self is constituted through webs of interlocution in a defining community (Taylor, 1989). This connection between our sense of morality and sense of self means that one of our basic aspirations to satisfy is the need to feel connected with what we see as good or of crucial importance to us and our community.

In the dialogical self, we have certain fundamental values which lead us to basic questions such as "… what kind of life is worth living? … What constitutes a rich, meaningful life, as against an empty, meaningless one?" (Taylor 1989, p. 42). Hence, connections between notions of the good, understandings of the self, the kinds of stories and narratives through which we make sense of ourselves, and conceptions of society, evolve together in loose packages. The story told reconciles the story-teller's current being with his/her past being. It makes the story-teller understand both the current and the past, and, therefore, allows them to reconcile and forgive each other. Within the context of temporality, the forgiveness and reconstruction of the current and the past "being" will constitute the reconstruction of a new "being". When people lose their loved ones through death as a result of HIV, they often find themselves experiencing breakdown and disintegration, and are forced to make sense of events through the utilization of stories or narratives. Stories play a central role in the process of identity construction. As (Mair, 1989; Elliot, 2005; Pinnegar & Daynes, 2006) stated that stories are the womb of personhood and can make or break us as we construct them within ourselves. Stories can sustain us in times of trouble and encourage us towards ends we would not otherwise envision.

Broyard (1992, p. 21) argues, "….. always in emergencies we invent narratives. We describe what is happening as if to confine the catastrophe." It is through understanding your past that your present will be clear and your future vividly clear. A reconstructed self-identity is based on the idea that reality is a product of one's own creation; each individual sees and interprets the world and their experiences through personal belief systems. It is within this context that I felt that the study of this nature is justified and significant as it traces the journey travelled by the surviving HIV positive spouse after the loss of a partner to an HIV related illness.

## 1.6 Operational definitions

### 1.6.1 Forgiveness

Forgiveness for the victims refers to a conscious decision to free themselves of negative power that the offense and the offender have over a person while not condoning or excusing the actor (Zehr, 1990). Letting go of the negative power usually refers disconnecting from the trauma or releasing bitterness and vengeance. Forgiveness is intra-individual, pro-social change towards a perceived transgressor that is situated within a specific interpersonal context (McCullough et al., 2000).

### 1.6.2 Reconciliation

Worthington (2005) defines reconciliation as re-establishing trust in a relationship after that trust has been violated. Reconciliation is a social act of repairing a relationship and it occurs between or among people.

### 1.6.3 Dialogical self

Dialogical self is based on the assumption that there are many I-positions that can be occupied by the same person. The "I" in the one position, moreover, can agree, disagree, understand, misunderstand, oppose, contradict, question, challenge and even ridicule the "I" in another position (Hermans & Kempen, 1993).

### 1.6.4 Self-identity

Self-identity is not about our inner essence, about how we feel we are and exist in the world; it is about a complex and continuous profiling of who we are in relation to society that marks us as individuals. Manning (1992) asserts that self-identity is about our data trail, how society keeps tabs on us and ascribes or imputes a personal or individual identity to us.

### 1.6.5 Reconstruction

Reconstruction means re-building what has been destroyed on the same site, but giving it a new face or re-building on a different site, but using the same materials from the old structure.

### 1.6.6 Self-identity reconstruction

This reconstruction of self refers to trying to make sense of one's changed self through narrative recollections. This occurs through the telling (to one's self and others) of stories which integrate the meanings that experiences provide to the view that people have of who they are now in

relation to who they were in the past, and where they see themselves in the future. This happens after the initial self-identity was lost or damaged.

### 1.7 The structure for the thesis

This thesis is organised into seven chapters and broken down as follows:

1.7.1 Chapter 1 highlighted the background to the study, cited problem statement, justification of the study, research questions and operational definitions.

1.7.2 Chapter 2 is the review of literature relevant to my topic under study. I looked through papers and previous research that explore the issues of surviving HIV positive spouses in order for me to identify gaps and chart the way that could assist in tracing self-identity reconstruction.

1.7.3 Chapter 3 is the discussion of the dialogical-self theory as a theoretical framework with which the study is seen and judged. It formed the basis on which the findings were discussed and conclusions drawn.

1.7.4 Chapter 4 looked at methodological framework for conducting qualitative research within a dialogical self-constructivist paradigm. The chapter also looked at research design, target population, sample and sampling procedure, research instruments, and data collection procedures and data analysis.

1.7.5 Chapter 5 looked at the findings through data presentation, analysis and interpretation.

1.7.6 Chapter 6 is the discussion of findings. This is where I engaged with the findings in relation to both the theory and literature and gave my own understanding on what the findings mean about self-identity reconstruction.

1.7.7 Chapter 7 is the concluding chapter of the study. In this chapter I gave a statement on what I believe this study achieved and its contribution to the field. I also stated what I observed as the limitations and how future research in this field could be advanced in the form of recommendations.

### 1.8 Chapter Summary

In this chapter I focused on the need to conduct a study on the track of self-identity reconstruction among the surviving HIV positive spouses. I did this by focusing on what HIV

positive status could do to self-identity and highlighted the role forgiveness could play in recovery after a loss. The chapter further engaged the issue of stigma and discrimination among the surviving HIV positive spouses as a justification to carry out this study and finally, the chapter gave the layout of the thesis.

# CHAPTER TWO
# REVIEW OF LITERATURE

## 2.1 Introduction

In this chapter, the literature from a social-psychological perspective was reviewed to gain an understanding of notions of and indicators of self-identity. The emerging new self was reviewed through engaging the literature on the experiences of HIV positive married people, and widows and widowers who are HIV positive. In Zimbabwe in 2018, 1.3 million people were living with HIV and the number of new HIV infections among uninfected population over one year among all people of all ages was 2.79% and HIV prevalence among adults (15-49) years was 12.7% (UNAIDS, 2018). Despite the decline in new infections, HIV-related illnesses continue to be the leading cause of death among Zimbabwean adults. The top three health threats facing the people of Zimbabwe are HIV, tuberculosis (TB) and malaria. HIV is increasingly recognised as an illness that affects couples and families, and not just the individual. This is not only because the virus can be passed on from one person to another, but also because for every person infected with HIV, there is a family and the community that are also affected.

## 2.2 HIV in Marriage

HIV presents a unique, complex phenomenon within the context of marriage. Though marriage has legal and customary definitions which vary depending on location and context, it is taken to include a matrimonial union between partners who share special expectations, privileges and obligations between themselves, their children and their immediate families. HIV, when introduced within marriage, brings forth reality challenges that are less frequent outside of marriage. The most dominant mode of marriage in Zimbabwe is the heterosexual monogamy marriage; polygamy unions are present but not as common and homosexual marital unions are not provisioned for by the law (Hallfors, Iritani, Zhang, Hartman, Lusenzo, Mpofu, & Rusakaniko, 2016).

Marriage, amongst its many other functions, is seen as a means and a barrier to protecting men and women from sexually promiscuous behaviours associated with increased HIV risk. Marital unions, unless stated otherwise, carry the expectation of intimate and sexual exclusivity between the parties within the marriage alliance (Maphosa, Mutandwa & Nyamayaro, 2017). However,

this is far from reality in many marriages, especially within Sub-Saharan Africa where cultural expectations offer room and excuses for infidelity. These predispose persons within marriage to the risk of HIV infection. With HIV being predominantly spread through sexual contact, when HIV is diagnosed in either one, both or all of the parties bound through marriage, it evokes various responses that may affect the lived experiences of parties within the marriage arrangement.

Research by Borquez, Cori, Pufall, Kasule, Slaymaker, Price et al. (2016) and Nalugoda, Guwatudde, Bwaninka, Makumbi, Lutalo, Kagaayi et al. (2015) cemented the assertion previously made by Population Action International (2008) that individuals within marriage, for a huge part of Sub-Saharan Africa, are at a far greater risk of being infected with HIV. The study by Borquez et al. (2016) sought to develop a mathematical model predicting future HIV incidence and used cohort data from previous studies conducted in Zimbabwe, Malawi, Tanzania as well as from the research by Nalugoda et al. (2015) who assessed the risk of incident HIV infection by marital status in Rakai, Uganda. The model was then applied to estimate incidents in Kenya, Malawi, Gabon, Swaziland, Zambia and Rwanda. The study revealed that for all countries in the study, with the exception of Swaziland, individuals in marital or cohabitating unions contributed to the largest proportion of all new infections with the figure ranging from 39% to 77% depending on location.

Cultural practices and societal expectations, according to Kposowa (2013), often place individuals in marriage alliances at a risk that is 4.3 times more likely to contract HIV. Extramarital sex remains one of the predominant means through which HIV infects persons within marriage. Sub-Saharan Africa continues to hold a relaxed attitude towards extra marital sex particularly regarding males in marital unions and the negative attitudes towards condom use within marriage places individuals at a greater risk of HIV infection. Research conducted in Kenya cited in Zakarsa, Weiser, Hatcher, Weke, Burger, Cohen, Bukusi & Dorkwin (2017) and the Population Action International (2008) revealed that 11 per cent of males who undertook the study reported to have had extramarital sex with an extramarital sex partner compared to two per cent of females within the past year. Higher incidences of extra marital sexual relations predispose individuals in sexual unions to a greater risk of being infected with HIV.

HIV permeates the marital system because the major means of prevention against HIV are not readily acceptable for married individuals. These include mutual fidelity, abstinence and condom use. Abstinence is not readily acceptable within a marriage union, mutual fidelity is hindered by a dominant patriarchal culture and masculinities which permit promiscuity and polygamy and condom use is perceived as culturally inappropriate and as accusatory of infidelity as well as lack of trust in the other partner where marital bonds should be built on trust. Even though married persons acknowledge knowing the risks associated with these behaviours and confirm to have been educated about them in the past, these behaviours, particularly extramarital sex, still continue unabated (Maia, Guilhem & Freitas, 2008 ).

Polygamy, another marital cultural practice common to Sub-Saharan Africa and Gwanda South in particular, has been identified as increasing the vulnerability of individuals within marriage to HIV infection. To clarify and validate this assertion, Fox (2014) conducted a study which utilised demographic and health surveys with HIV biomarkers for sixteen African countries. The research was designed to assess the relationship between individual HIV infection and formal and informal sexual concurrency among married men and women. The research concluded that even formal marital concurrency in polygamous unions was associated with greater HIV infection risk at an individual level. This conclusion, however, is rebuffed by Reniers and Tfaily (2012) who investigated the relationship between polygamy and HIV infection using internationally representative survey data with linked serostatus information from twenty countries within Africa. The study found that though junior wives in polygamy unions are more likely to be HIV infected than spouses of monogamous men, HIV prevalence was actually lower in populations were polygamy was practised extensively.

Post infection marriage life is associated with unique realities and possibilities in Africa. One of the formative reactions post identification of infection is the emotion response of anger. This anger, rage and hate are often directed at the person believed to have been responsible for infection. As HIV is predominantly spread through sexual intercourse, it is rational to believe that the virus was brought into the marriage union through extramarital sexual intercourse. Accompanying feelings of betrayal have been reported by Fitness (2001) as triggering separation and divorce after couples had identified their HIV serostatus. Severance of marriage ties often leads to the development of new sexual partners, sexual habits or even in new marital alliances

all of which increase the risk of exposure of other individuals to HIV infection as well as the divorcee to re-infection.

Persons infected by their partners often report having observed, suspected or having had evidence of infidelity of the other partner. To these couples, diagnosis of infection does not necessarily come as a shock due to reduced level of trust after observing incidences of infidelity. However, the response to diagnosis are also usually negative with respondents in a research by Magura (2015) citing feeling disappointed even though they had suspected that a similar fate would befall them. Respondents also reported that even though they had at some stage considered separation after being diagnosed, it was not feasible. Chief among the reasons cited for remaining in the marriage union in spite of being seemingly betrayed and infected was that desertion would not change the acquired HIV status. Peta (2017) states that the major reason for women staying with their husbands after being infected with HIV was that they are economically heavily reliant on them. Respondents also cited concerns over raising children from broken homes, highlighting that it was important for the future of their children that both parties continue with their marital union.

Infected couples often choose to remain together and even in these circumstances, marital relations are often strained. One of the reactions and challenges reported by men in HIV positive marital unions pertains to sex denial. Fitness (2001) reported that women withheld sex from their partners as part of an emotional and behavioural reaction to being diagnosed as HIV positive. This in turn stimulated the search and introduction of extra marital sexual partners, further strengthening the vicious cycle of distrust, betrayal, infection and re-infection.

When individuals within a marriage set-up become infected with HIV, they adopt various coping strategies that have the potential to help them adjust to cope with living with HIV as well as hinder normalcy. According to Magura (2015), one of these coping strategies is developing an ‘us versus them’ attitude and mentality. Sharing that attitude within a marital union can be very helpful in fighting the rumours associated with being HIV positive as well as providing psychosocial support for each other. However, the same attitude may be detrimental when there is sero-discordance, leading to increased tension and infighting. Often in the minds of those who are positive, the other partner is at fault for being HIV negative.

The position of women within marriages in Sub-Saharan Africa impedes their ability to negotiate safe sex (Peta, 2017). Women are heavily dependent on their husbands for upkeep and financial resources. This, combined with gender based violence and societal expectations of sexual behaviour in marital unions, represent a trend that remains prevalent in Sub-Saharan Africa. This is true to the rural Zimbabwean context where many women within marriages are often inhibited from exercising their reproductive right to safe sex. The inability to negotiate safe sex even when infidelity is suspected means that there is increased risk for infection and dual infection. It also leads to re-infections for the already infected, increasing morbidity rates for the infected as well as reducing their life expectancy. Mugweni et al. (2015) argue that women who are widowed as a result of HIV related illnesses in the developing world face a number of obstacles. For example, they may be blamed for their husband's death or ostracised by the community as a result of the stigma attached to HIV. Discrimination against widows and HIV are interrelated in two ways, HIV significantly adds to the burden of the already inferior of widows and their economic, social and political inferiority makes widows more vulnerable to HIV infection. Patriarchal order has left many Zimbabwean women more vulnerable to HIV infection as they remain subservient to men with no negotiating power in sex matters.

HIV within the marriage union also presents a scenario where one individual within the marriage is infected and the other is not, a phenomenon referred to as HIV serostatus discordance. Reaction to serostatus discordance has been found to differ between males and females within marriage. Bunnel et al. (2007) found that women are more likely to remain with an HIV partner when they themselves are HIV negative. As aforementioned, when individuals inside a marital union get infected with HIV, infidelity is suspected. However, society is particularly relaxed regarding infidelity committed by men; it is very unforgiving for infidelity committed by women. It is common for men to react to perceived infidelity by severing marital ties and this reaction is even more common where HIV is involved. This reaction is fortified by the societal belief that HIV is a disease of loose morals and multiple sexual partners.

As a result of the negative reactions that are common between couples when they discover that they are infected with HIV, there is a tendency among marital unions not to disclose one's status unless the other person has identified and disclosed theirs. Thompson (2000) observed that women felt stigmatised and were afraid of disclosing as a result of societal discrimination. Due

to fears of potential isolation, backlash, violence and stigmatisation when an individual within a marriage union is diagnosed with HIV they may potentially hide from their partners. This impedes the infected partner or partners from getting treatment, thus increasing the time gap between diagnosis and treatment as well as increasing the risk of re-infection which negatively impacts health outcomes reducing life expectancy for them. Mugweni et al. (2015) noted that the other partner may not be infected at the time of diagnosis and failure to disclose HIV serostatus may lead to infection that could have been potentially avoided.

Women, who are not infected with HIV, within marital unions which are sero-discordant, can end up infected with HIV. Traditional gender roles impact the women's decision-making powers and influence while increasing their vulnerability to HIV infection. Discordant couples interviewed in a research by Bunnell et al. (2007) highlighted that one of the challenges they faced was with regards to negotiation of condom use and abstinence. They also reported that they would yield to the demands of unprotected sex as an attempt to quell reduced sexual intimacy and tensions that came with constant debates about sex and in some instances the need to have more children. A report by USAID (2010) revealed that in a study including nearly 600 discordant couples from Zambia and Rwanda, 79% sero-converted or became infected within the first year highlighting the eventuality of concordance within marriages. Divided along gender lines, 75% of men sero-converted or became infected whereas 84% of women sero-converted or became infected, highlighting the assumption that women wield lesser power and influence than men in advocating for preventative measures against infection.

Research has revealed that partners who are tested together are more likely to stay together regardless of whether the couple is discordant or concordant (Tabana, Doherty, Rubenson, Jackson, Ekstrom & Thorson, 2013). This is partly because they get the chance to disclose their results within a professional set up with a trained counselor who then educates them on life as a discordant couple or as an infected couple. The development of a support system for the infected helps them cope better with being infected as well as adhere to prescribed treatment and treatment procedures.

However, married life while infected with HIV is not all doom and gloom. Other couples have reported to adjusting well and living positively as concordant and discordant couples. Though facing challenges similar to any other married couples, they have remained steadfast building

productive relations and maintaining a family of children who due to following medical advice were born without HIV infection. Straube (2013) discusses how couples who immediately embrace the reality of their situation and adopt an alternative lifestyle that strengthens positive health outcomes have a greater chance of living fulfilling lives where they can set lifelong goals together and attain them. However, to achieve this there is greater need to adopt positive attitudes as individuals, couples, families and communities, something that has not fully caught on in Sub-Saharan Africa.

### 2.3 The Self and Social-Psychology

The self is a mental construct representation of oneself that forms the content of human experience. The self pertains to how individuals think about themselves, how they evaluate or perceive themselves (Stanghor, 2013). It is the sense of personal identity, of who a person is as an individual. It is a mental picture a person has of himself or herself. The concept of self within social psychology looks at how individuals view their behaviour, abilities as well as unique characteristics. The self enables individuals to relate to others. What constitutes the self is a subject of great debate but self is largely a product of self-concept (Hattie, 2014; Moutoussis, Fearon, El-Deredy, Dolan, Friston, 2014; Elliot, 2013).

Self-concept is loosely referred to in literature as self-knowledge (Showers, Ditzfiels & Zeigler-Hill, 2014). The self-knowledge pertains to all gathered knowledge that an individual employs to define him or herself. It is this knowledge, though at times inaccurate, that forms an individual's belief about themselves and their attributes (Baumeister, 2013). The knowledge of self is developed through many ways, most of which are captured in social psychology theory. The self-concept is developed through the concept of the looking glass self (Gould & Howson, 2015; Dennis & Smith, 2015).The looking glass self theory's explanation to the development of the self asserts that individuals shape an identity of themselves based on the perceptions of others. The image of the self comes from our self-reflection and from what others think of us. An individual, in forming a self-concept, imagines how he or she appears to other social beings. The individual then imagines how others will perceive and judge him or her based on that appearance. The individual forms a mental picture of how he or she appears to others and may modify his or her image and behaviour so as to align it with how he or she wants to be viewed by others (Isaksen, 2013).

The concept broadly applies to how persons infected with HIV may form an image of themselves. After realizing the presence of infection, an analysis of how others will view them follows. In the marital context, this may be how the other partner views them in the long run now that they are infected or how the relatives of the other spouse will view them once they find out that they are infected. If the analysis brings out that the partner will view them as sexually immoral or nauseating because they are infected, then the reaction to this evaluation may be self-loathing on the part of the infected person (Kordick, 2013). This is often a consequence of an internal conversation where the person discusses within himself/herself the popular reaction to this circumstance or the probabilistic response they may expect from the persons concerned.

The knowledge of the self is also enhanced through the mental process of introspection also referred to as self-inspection (Kross, Bruehlman-Senecal, Park, Burson, Dougherty, Shablack, Bremner, Moser & Ayduk, 2014). Introspection is an individual's subjective analysis of their internal states. These internal states include emotions, attitudes, thoughts, feelings and beliefs, behaviours which are not overtly observable to others, but subsequently hold influence over overt behaviour. By evaluating how they feel or think particularly in certain instances and in response to certain behaviours, a person gains greater understanding of their self (Harmon, 2013).By evaluating these, individuals get a greater understanding of their behaviour and where due modification may be requisite or necessary individuals would change their behaviours to fit the new situation they find themselves in. The content of introspection, particularly the language one uses to describe to themselves in self-talk, the contents of the analysis, can affect one's regard of their person particularly self-worth and self-esteem (Kross et al., 2014). Negative contents or perceptions of oneself in self-talk can dramatically reduce self-esteem and self-confidence. It, therefore, would mean the HIV positive individuals would need to have a greater knowledge not only about themselves but also about HIV and how it is transmitted. There is need for the empowerment of HIV positive people for them to navigate the HIV terrain with ease.

Personal identity is also developed through social comparison, a process through which individuals analyze their behaviour and appearance and contrasts it to other individuals (Suls & Wheeler, 2013). By looking at others, we can evaluate our behaviour and appearance. Through this evaluation, we form an image of how we perform to the standards set by others. An upwards

social comparison occurs when we compare ourselves to individuals who are better or have a more positive outlook than us, results of which can either be demotivating or motivating depending on the perception of the gap that exists between the two concepts. Upwards social comparisons can negatively affect someone's perception of their self if they feel the distinction between their characteristic is huge compared to others (Tyler, Kramer & John, 2014). According to Pryor and Reeder (2015), this is a possibility when a person feels that being infected with HIV has transformed them radically from the norm shared by other persons. A downward social comparison occurs when an individual compares him or herself to someone with seemingly inferior qualities, results of which often make a person feel positively about their self-image.

The self-perception theory also explains how individuals develop a sense of self through an inference into their behaviour (Schwarzer, 2014). An individuals' behaviour can add valuable insight into their true states and can help them develop a more accurate understanding of themselves. According to Green and Murphy (2014), self-perception is often employed where the inspection of internal states does not produce effective results. The self-perception theory applies to when an HIV positive individual has developed a negative outlook regarding their health outcomes, holding firm the belief that they will soon pass on and as such, loath the person responsible for infecting them. However, with the passage of time and with seeming no issues of bad health, a new perception of the self is formed that encompasses someone who is strong in the face of HIV and who would not easily succumb to illness which may reshape the attitude and anger directed at the person responsible for infecting them (Pryor & Reeder, 2015).

Feedback from other individuals is key to the development of a self-concept (Stanghor, 2013). Feedback pertains to the reaction behaviours of others to our appearance and behaviour. The reaction has to conform to the expected response to displayed behaviour for the self-image to be fortified. For instance, an HIV infected person within discordant marital union who believes that he or she is now nauseating and undesirable after being infected will have this perception fortified when he or she notices that his or her partner is no longer comfortable with intimacy with them. The feedback from others aligns to their perceived self-concept and as such develops and fortifies it. Contrarily, where behaviour feedback does not align with the perception of self-concept, the image of the self is usually realigned to match the feedback from others.

Individuals seek to develop an understanding of the self in response to the appraisal motive. This is an inherent desire held by individuals to know more about themselves. Individuals possess a desire for accurate and certain evidence regarding their traits and abilities and evidence that confirms their self-assessments (Cohen & Sherman, 2014).This is born out of the need to reduce uncertainty by increasing consistency, as such, gaining more ability to predict and control the environment (Stanghor, 2013). When individuals know about themselves and have a developed self-concept, they can modify themselves to suit the need for affiliation or modify their behaviour and perceptions to avoid any negative emotions that result from a negative self-perception. More so, seemingly knowledgeable conversations can be held within oneself and can lead to knowledge based decisions that reduce any cognitive dissonance.

Individuals also seek to gain an understanding of the self in response to the desire to improve and enhance themselves (Cohen & Sherman, 2014).Other individuals offer the standard an individual should strive to match and/or to surpass in order to attain positive growth. A person can only be sure of personal development if they know their current state; hence, the need for HIV positive people to understand what it is to be HIV positive. It acts as a point of reference, a point of departure where one looks in order to measure growth. For instance, if an individual wants to enhance their personal appeal, they first have to know the current level of appeal their self has and then add enhancements that will develop their appeal. In addition, individuals want to confirm what they already believe about themselves, a motive known as the self-verification motive.

Knowledge gained of the self builds an individual's self-awareness which could help individuals who are HIV positive to live positively with HIV. Self-awareness refers to the extent to which an individual is currently fixing his or her attention on his or her self-concept (Kirkpatrick & Rusch, 2016; Csikszentmihalyi, 2014). Self-awareness is sub-grouped into public and private awareness. Private self-awareness is the knowledge of one's internal states which are not directly observable to others. This includes an individual's beliefs, attitudes, thoughts and emotions, particularly in response to certain stimuli like being HIV positive. Public self-awareness is developed by gaining knowledge of oneself through the behaviours and perceptions of others. Public self-awareness refers to knowing the self that is viewed by others, and understanding of the image you portray to others in the event of stigma and discrimination for those who are HIV positive.

The behaviours that others show towards a person help a person form an idea of the image he portrays and how that image appears to others.

A person's self-concept has great influence on their self-esteem. Self-esteem refers to the judgment upon evaluation a person has of their self and is usually defined as high or low depending on whether an individual evaluates him or herself positively or negatively (Stanghor, 2013).Self-esteem is often a product of how individuals perceive the reaction of other people to their behaviour, how they evaluate any comparison to others and the value they give to the roles and behaviours they perform. Self-esteem has the potential to impact the content and nature of evaluation a person has whilst engaging in self-talk and is an essential influencer in the self-identity reconstruction.

The self is also divided into the agent self (Showers et al., 2014). The agent self performs an executive function of coordinating behaviour in response to thoughts as well as facilitating conversation between the various components of the self. The agent self is responsible for self-presentation which is the image a person presents to others as well as self-regulation which entails the coordination and the management of the image presented to others as well as the patterning of thought and the internal conversation held within the self. This could be equated to the denial of being HIV positive and putting much effort to live positively with HIV. HIV positive individuals could engage themselves in tasks such as motivational speaking, improve themselves academically or engage in any prosocial behaviour in the community as a way to project a self to others that is very strong.

Self-identity stems from the differences that we have as individuals in the context of others (Karamouzian, Akbari, Haghdoost, Setayesh & Zolala, 2015). Arendt (1958) cited by Hermans (2013) proposed that if people were the same, there would be nothing to say about our existence, if they were somewhat not the same, there would be nothing understandable about being human and the more similar experiences we have as humans help us understand each other through inferences on experiences. Hermans and Hermans-Konopka (2010) argued that the self and self-identity operate in a similar fashion; these two entities utilise the alter ego as an intrinsic feature of the self-extended in the social environment. Hence, self-identity becomes an attribute shaped by the social status quo and the receptivity in the individual labeled as such (Karamouzian et al., 2015).

Self-identity among people living with HIV was observed to have been altered and that alteration seen as a result of personal choices by most people (Kleiber, Hutchinson, & Williams, 2002). This was mostly attributed to what is perceived as bad behaviour, that is, extra-marital sexual encounters (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012), injecting of drugs through needles (UNAIDS, 2013) and random and opportunistic sexual behaviours (Rhodes, Malow, & Jolly, 2010). The perception that the contraction of HIV is due to a preferred lifestyle has a significant impact on internal dialoging individuals go through. The choices, the decisions and opportunities that an individual chooses become a reflection of how they choose to live in harmony with society (Friedman & Rossi, 2011). Internal dialoging provides a basis for justifying why others do not disclose their statuses, how the widowed or widowers chose to live after losing a partner to HIV-related illness (UNAIDS, 2013), how they build or destroy relations that interfere with their psychological wellbeing and happiness (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012) and, lastly, how they determine what is good for them independent of societal expectations.

The identity of people living with HIV is fluid and non-linear as was observed by Moses and Tomlinson (2013). This observation is further highlighted by Auerbach, Parkhurst and Cáceres (2011) who articulated that access to resources often determined the degree of family and societal stigma and discrimination that impacted on the self. Disintegration of one from the family was usually fuelled by perceived dependence and care seeking behaviour (Ekstrand et al., 2013). However, Karamouzian et al., (2015) argued that despite economic independence, the spoiled identity experience was inevitable to every individual who suffered from HIV and, as such, money only masked the effects. Individuals with money quickly transferred their power and authority to monetary value and maintained their social standing from a capability point of view (Ekstrand et al., 2013). This would mean that individuals who are poor would find it difficult to mask their HIV positive status as they rely on public funding for their medication and would make them attend public hospitals and counselling services. This would, therefore, make them lose any privacy as they would be seen when they attend the Opportunistic Infection Clinic (OIC) departments which deal with opportunistic infection diseases.

Aryle (2015), in his study on the implication of HIV in the Nepal Region, observed that the concept of HIV had significant connotation that influenced the development of self-identity. The research identified two types of self-identity, with which the majority of individuals that were

suffering from HIV were categorized as falling within the realms of the self (Hareb, 2011). The first is 'the spoiled self' which emanated as the hated, disgraced, undermined and discriminated self that individuals within the community despised (Auerbach, Parkhurst & Cáceres, 2011; Moses & Tomlinson, 2013). The second is the imaged futuristic self that an individual is working on in his/her reconstruction. Accepting the current status needs hope for the future with new self-identity. This requires self-conversation within a surviving HIV positive spouse, a dialogue that would pacify the current self with the imaged futuristic self. In another study, Li (2015) argued that the spoiled self was the major area of concern that impacts on the development of personality and identity amongst the surviving spouses in the Southern Africa region.

The transformation of the self from the spoiled to the reconstructed self was observed as a journey that demanded courage and tolerance amongst the surviving individuals to the HIV pandemic (Aryle, 2015). The discovery of the cause of death of a loved one triggered tensions in social relationships with the significant others (LaRocca & Scogin, 2015). Thus, Taylor and Usborne (2010) identified phases and periods that marked the experiences of the surviving spouse as characterised by life before the discovery of HIV and life after the death of one's partner due to HIV-related illness. The relationship between the surviving spouse and other family members deteriorates, triggering some form of an identity crisis (Aryle, 2015). The identity crisis affects the general function of the surviving spouse in determining their roles and responsibilities within the family genome (Rhodes, Maslow & Jolly, 2010). In most instances, as supported for by LaRocca and Scogin (2015), the love and respect that once existed evaporates and the majority of the family members may disconnect and sever social and economic ties with the bereaved spouse.

Almost all participants in Aryle (2015)'s research had experienced spoiled identity from a societal perspective. The social distancing from societal member influences a reciprocal response in the surviving spouses by which they socially isolated themselves from involvement in a social grouping that undermined their capacity as human beings (Ekstrand et al., 2012). Social affiliations and interactions cut off gradually as a feeling of unwantedness encroached in (Auerbach, Parkhurst & Cáceres, 2011). Findings from Aryle's study (2015) further indicate that

females and young children faced significant discrimination that disoriented their capacity as human beings at both family and societal levels.

Comparisons between the self and others become the major area of concern in the development of a viable identity in the surviving spouse (Rhodes, Malow & Jolly, 2010). The ideological and philosophical conceptualisation of HIV as a degenerative disease and its comprehension by society as equivalent to the development of mental deterioration affect the general interaction between the surviving spouse and other community and family members (Auerbach et al., 2011). The discordant interaction between the infected and those affected, but with sero-negative status impacts in both negative and positive ways on self-identity and the interactions that occur through the dialogical self. These interactions influence the feeling of worthy (UNAIDS, 2013), interacts with individual self-esteem (Gallart, 2017), has a bearing on self-efficacy in life and social roles (Kleiber, Hutchinson, & Williams, 2002) and lastly has a significant role in determining how the surviving spouse will perceive themselves in the context of others (UNAIDS, 2013). Spoiled identity in this instance was equated to a life in prison sentence as compared to HIV free life in freedom. This triggered the misconception about HIV significantly negatively impacting on the self-perception of individuals living with the disease (Pawelczyk, 2013; UNAIDS, 2013).

The anticipated early death amongst those suffering from HIV impede on the existential perception significantly affecting their orientation towards plans of the future (Schafer, Ferraro & Mustillo, 2011). The crisis in identity resulting from anticipated early death influenced the majority of individuals to give up on their lives as evidenced by research carried out in the early 90s. The majority of people did not know the cause and effects of the disease and as such hyper discrimination and stigma negatively affected the psychological wellbeing amongst the infected (Rai, Dutta & Gulati, 2010). Experiences of hedonic happiness and eudemonic expectation of life became restricted as argued by (Hsiung, Fang, Wu, Sheng, Chen, Wang, & Yao, 2011). Rai et al. (2010) further articulated that suffering from HIV during this period was death experience in itself. The physical deformation and the perceived psychological incoherencies in interactions intensified negativity from community (Ekstrand et al., 2012). Furthermore, UNAIDS (2013) observed that limited knowledge and understanding at both community and individual level triggered social problems that became bigger than the biological experience of HIV, significantly

leading to early death and disenrollment of the infected especially in individuals from rural parts of Africa in countries such as Kenya and Tanzania.

LaRocca and Scogin (2015) illustrated that lost hope and the decline in physiology accompanied by lowering of self-esteem, worthy and efficacy influenced the development of an identity crisis. These states were achieved through consistent negative interactions that occurred within an individual (Taylor & Usborne, 2010). Constant internalised self-criticism by HIV positive individuals and continued evaluation of unworthy in the face of other individuals triggered elements of disharmony in the experience of life. Labels and the negative connotation of being HIV positive laid a foundation for the self-fulfilment prophecy and subsequently influenced their overall general function in the community they belong to (Moses & Tomlinson, 2013). With a lowered esteem accompanied by the death of a significant other, control over kids and other relatives were lost and the capacity of parenthood undermined in social relations (Rhodes et al., 2010).

A study conducted by Alicke, Dunning and Krueger (2005) at the University of Oregon and the University of Cologne indicated that self-identity measures were high amongst those living with HIV but coming from affluent home. This was also supported by evidence that was gathered from Britain and Spain that highlighted that successful and powerful people were not afraid to reveal their statuses (Rhodes et al., 2010). The general assumption from this study was that money and influence outweighed the stigma (Ekstrand et al., 2012). On the contrary, low self-identity measures were noted amongst the majority of young adults in the Sub-Saharan region and West Africa with evidence indicating poverty as a major factor. These low scores were also observed amongst the Arabs in Saudi Arabia with the influence of religion as the most prominent factor (Speakman, 2012). HIV and identity in individuals was misconstrued (Metcalfe, 2011) in Saudi Arabia, the general population identified individuals suffering from HIV as promiscuous and infidels. In Nepal as posited by Aryle (2015), physiological build contributed significantly to self-identity and individual statuses, as such, the physical appearance of an individual played a crucial role in how society identified and respected them.

One of the most popular factors that were identified to impact on self-identity in Nepal was family disintegration and enmeshment (Auerbach et al., 2011; Alicke et al., 2005). This phenomenon was prominent amongst families that had children of ages 15 to 25 (Auerbach et al.,

2011). Most of these children presented the capacity to process information on what caused the death of their parent and such understanding contributed to their nature of relationship with the surviving parent (UNAIDS, 2013). Other parents who were blamed lost their role as parents and the respect and trust facilitating an identity and role confusion in the family setup (UNAIDS, 2013). Moreso, with the anticipated need for care and assistance in the form of treatment from their children, the parents surrendered their domineering social relationship with their children (LaRocca & Scogin, 2015; Auerbach et al., 2013).

The economic identity tied to status was interfered with in most parts of Africa (Cameroon, Nigeria, Kenya, Malawi amongst others) through firing and work discrimination from the period 2000 to 2008 when HIV was not closely understood (Elad, 2008). Most individuals were sent out of work; hence, with the loss of the loved ones to the pandemic, most individual became exposed to low income and to poverty circumstances on a daily basis (Taylor & Usborne, 2010). This identity crisis was attached to economic stigma and discrimination, triggering an internalised reduction in feeling worth (Moses & Tomlinson, 2013). The continued discrimination and undermining of individuals due to their statuses inclined the status of HIV to become an identity of the surviving individuals living with HIV (UNAIDS, 2013). Evidence from research carried in Nepal by Aryle (2015) indicated that most women suffered an identity crisis more than males due to gender related stigma plus the status of HIV. These women were ostracised, discriminated and stigmatised against by their communities, friends and relatives (Maphosa, Mutandwa & Nyamayaro, 2017).

The concept of the self in the context of HIV and AIDS amongst spouses living with the disease triggers various factors into motion (Aryle, 2015). Self-identity, thus, consists of contradictory identities which pull individuals in different directions making identities shift consistently on a continuum (Hermans & Hermans-Konopka 2010). Self-identity influences human behaviours, hence, in a study conducted by Elad (2008) in Cameroon on how health care providers assisted those in need indicated that upon being given the responsibility and an identity of nurse, their performance became an externalised expression of the way they wanted their field perceived. Along these lines, self-identity is formed and built with the intention of fitting within the realms of society (Maphosa, Mutandwa & Nyamayaro, 2017).

Surviving HIV positive spouses are in constant dialogue with their selves, challenging what could have been if they had taken an opposite direction (Taylor & Usborne, 2010; Salgado & Hermans, 2009). This is coupled with society's influence in providing a bridge that acknowledges the extension of the self to the local and global environments. Therefore, the collective voices of groups, the power games within the family dynamics targeting the surviving spouse and the negative energy from the children trigger psychological problems for the surviving spouse. Evidence from Elad (2008) on lived experiences of spouse surviving with HIV in Cameroon demonstrated that the relatives and other family members influenced the behaviour of the surviving spouse's children. The evidence also pointed out that hate and blame on the surviving spouse even influence the children to blame their surviving parent as the cause of the death of their parent (Hermans, 2013). The level of tolerance and constant dialoging in the individuals receiving blame either resulted in self-hate or increased resilience.

### 2.4 Widowhood and widower hood

The eventuality of existence is death and for persons in marital unions this means that they will have to endure widowhood or widower hood, except for tragic circumstances the persons pass on simultaneously. Widowhood or widower hood refers to the life experiences that a person who has lost their spouse goes through (Zaroba, 2016).Depending on relations pre-death, the state of finding oneself without their life partner can be a harrowing experience. The nature of life widowers and widows live are also massively influenced by the societies they live within. It offers new realities and experiences and the confrontation of issues that had not been exclusively dealt with while the other partner was still alive and the extension of others that were pre-existent before death. The realities are even more unique for persons who were living in a union impacted by the infection and presence of HIV.

Losing a spouse, like any other major life event, demands adaptation which varies across different individuals depending on their circumstance and the style and choices they make in the adaptation process. There are common sex differences with regards to adaptation and coping with being a widow or widower. According to Ogweno (2010), widowers have reported advanced social coping and adaptation after losing a spouse. She highlights that in Sub-Saharan Africa, men are the principal breadwinners and are naturally expected to get over the loss immediately and return to breadwinning duties. As such, men showed greater organisation after

the death of a spouse as well as a quicker return to social life normalcy which mirrored the life before the loss of the spouse. In the short term, men reportedly cope better emotionally with loss, however in the long term women coped effectively with loss. Ogweno (2010) highlighted that this was probably the result of the assertion that women take their time to effectively grieve the death of a loved one compared to men who are forced by demands to return to normal social functioning without adequately grieving the death of their spouse. Individual differences in resilience and emotional vulnerability can also impact the length of the grieving period.

After the loss of a partner, what follows next is a period of grief. Grief is described as a natural response to losing someone or something valuable, important and/or with greater emotional attachment to you (Parkes & Prigerson, 2013; Irish, 2014). The grieving process is an intense period of mourning characterised by shock and, in some instances, denial. There is a high frequency of negative emotions characterised with the loss of a close life partner such as sadness and stress which are most intense in the earlier stages of being a widow or a widower. For surviving spouses infected with HIV, the grieving process can potentially impact health outcomes as high stress levels lower immunity resistance opening the window for opportunistic infections. Often, surviving spouses may pass on in the immediacy of mourning the death of the marital partner.

The initial stages of being a widow or widower are characterised by great disorganisation. During the funeral process and before the burial of the spouse, much effort is centred on the deceased and his/her burial and all facets of life come to a halt. However life problems resume after burial and often the widow or widower is overwhelmed by the resumption of normal life while they are still in the grieving process. The period of disorganisation, according to Foster and Holden (2014), is also associated with feelings of restlessness and aimlessness with affected individuals reported to become more socially withdrawn and irritable. This forms the foundation of the diverse reactions individuals who have lost their partners to HIV-related illnesses go through.

After losing a partner to HIV-related illness, surviving spouses often engage in self-blame (Brion, Leary & Drabkin, 2013; Epstude & Jonas, 2014). In a research by Brion et al. (2013) on reactions to serious illness, specifically focusing on HIV, widows and widowers reported often ascribing to themselves the responsibility for the death of their spouses. Often such was the case

when the surviving spouse had engaged in infidelity which he or she suspected to have brought HIV into the marital alliance and had subsequently led to the death of his or her spouse. As such, the surviving spouse blamed themselves for having engaged in behaviour that led to the death of their partner and often used the word 'killed' as a verb to describe the effects that their act of unfaithfulness had impacted on the significant other. Self-blame was also reported by widows and widowers who had halted the marital alliance and had refused to take care of the health needs of the deceased often in response as an anger response to being infected (Epstude & Jonas, 2014).

Self-loathing often follows self-blame, with the surviving spouse engaging in self-hate. Self-hate is described as an intense dislike of oneself often as an anger response to unmet expected standards or behaviour. Self-hate was also reported among the respondents in the study by Brion et al. (2013) with patterns of self-hate often emanating from the belief that he or she is not worthy even to be alive as they had betrayed their life partner, the consequence of which led to the partner's death. Self-loathing has the capacity to drive the surviving spouse into engaging in self-deprecating and self-harm behaviours such as casual sex encounters with strangers leading to infection and reinfection, defaulting medical treatment, engaging in drug and alcohol abuse as well as committing or attempting to commit suicide. Though such behaviours can be common, extreme cases require intensive psychotherapy to assist the widow or widower to reshape cognition.

Such reactions to the death of a spouse severely impact life enjoyment and the quality of life that widows and widowers live. The loss of a spouse can also lead to reduced optimism for the future and in increased despair and hopelessness. The death of a spouse, especially in instances where it is due to HIV-related illness, brings forth the realization of the eventuality of death and challenges any existential beliefs a person may have help regarding living a full life while infected with HIV (Jonas, Naidoo, Roman, Gutierrez, & Fiexas, 2015). Constant thoughts regarding the death of one's partner and the eventuality of the thinker's death can constantly shape the widow or widower's mood, leaving a grave, dark and negative outlook of the future.

A different reality befalls the surviving spouse if the deceased spouse's infidelity resulted in the infection of the surviving spouse. According to Pryor and Reeder (2015), widows often report feeling anger at the dead spouse and feeling revulsion over things and objects concerned with or

related to the deceased. This anger and revulsion may lead to severance of ties with relatives and friends of the deceased as seeing them may constantly evoke ill feelings. Anger is usually a result of failure to find closure over the pain and suffering the dead and the death have inflicted on the widow (Ogweno, 2010). It often comes from the failure to confront the deceased while still alive to know why they made the choice to commit infidelity. Questions of self-worth may still linger for the surviving spouse, reflecting on whether they were not valuable enough or appealing enough that the deceased had to risk both their lives by engaging in extramarital sexual encounters.

The reality for surviving spouses can be extremely challenging in Sub-Saharan Africa. The cultural practices and attitudes held by communities can subjugate and humiliate the widow or widower. Often after the passing of a spouse due to HIV infection, relatives of the dead may undergo a witch-hunt to determine how and why the deceased passed (Dube, 2016). If the person has passed on due to progressed AIDS, often relatives of the deceased accuse the surviving spouse of infecting the deceased even in the face of no evidence. A blatant disrespect for the surviving spouse is common and this may impact the surviving spouse psychologically, worse, if the widow or widower was already in a phase of self-doubt and self-loathing. This may also drive anger and hatred towards the deceased for having left them to deal with this ire alone.

HIV positive widows face a severe form of discrimination referred to in literature as triple stigma (UNAIDS, 2017). This is the stigma of being HIV positive, the stigma of being an HIV positive woman as well as the discrimination of being a widow. This severely impacts the outlook to life and perception they hold towards their self. Stigma and discrimination lowers the self-esteem and self-worth of persons living with HIV as it implies that they are lower beings undeserving of normal human interaction. This may lead to anger towards other members of the society and often widows are alone with no alternative source of psychosocial support to deal with issues pertaining to discrimination and stigma (Maphosa & Maphosa, 2014). Widows also undergo some ritualistic practices that may not be aligned with the teachings given regarding living a positive life while infected with HIV. The widow cleansing ceremonies common in Sub-Saharan Africa places those who practise them at greater risk of contracting HIV as well as presenting cognitive dissonance for widows who have been taught how to live healthy and positively. In Kenya, among the Lou community, widow cleansing is practised extensively and at

the greater risk of the widow and the cleanser (Perry et al., 2014). When a woman's husband dies she must engage in unprotected sexual intercourse with a man who is referred to as a cleanser who removed the 'impurity' a woman would have acquired at the death of her husband. Women are effectively supposed to engage in this act and this may mean possibly infecting another person if they are not able to reveal that they are HIV positive due to the fear of being labelled as being behind the death of their husbands.

Widows in Sub-Saharan Africa are also subjected to widow inheritance (levirate). According to Evans (2015), widow inheritance is a process through which the widow is expected to remarry another man, usually a brother of the deceased, from the family of the deceased. Culturally this meant that the family of the deceased would still be cared for by his relatives and this would mean the financial needs of the family, especially the children are met which may not be necessarily the case if the widow married another man who was not related to the children. According to Maphosa and Maphosa (2014), the arrangement of widow inheritance was designed to cater for the welfare and needs of the family of the deceased. However, it fails to take into account the needs and sensitivities of the widow and such an arrangement is too simplistic and transactional especially when marriage is not sorely viewed as a means for welfare, but a union that contains emotional elements such as love, attraction and affection between marrying partners. Yet women in some communities are expected to undergo this process which can severely hamper a person's outlook of themselves if they are denied the opportunity to choose and reject. All these cleansing ceremonies appear to be designed and enforced on widows but not on widowers. Sleap (2001) argues that this affects HIV disclosure as disclosure becomes a decision making process and the framework consists of steps that involve dilemmas, barriers and decisions at each step. Individuals may require help in adjusting to the diagnosis and achieving a personal acceptance of such diagnosis. It takes a lot of thinking to understand a new self. A self who is now HIV positive, a move from 'us' concept to 'them' concept, 'them' who are HIV positive and 'us' who are HIV negative. There is a psychological strain of leaving the comfort of your perceived group to the new group of them who are HIV positive. This adjustment takes a lot of calculation. To disclose or not to, then becomes a daunting task under adjustment to the diagnosis.

Another challenge faced by widows and widowers pertains to remarrying. Sub-Saharan African communities place high value on family and marital unions and marriage is a goal set for everyone by the community and valued so highly that those who do not pursue it or are seemingly failing to gain it are chastised by the community (Dube, 2016). However, remarriage is not as straight forward as in Western countries. If the widow has not been subjected to widow inheritance, she has to ask the family of the deceased the permission to get married and approval is not always granted. The family of the deceased may feel that the children will not be properly looked after and may hold reservation regarding another man inheriting the property of the deceased for his own benefit. This disregards the loneliness and lack of intimacy that the widow might feel and seek to replace. The constant scrutiny of widows deprives them of a sense of self dignity and might eventually affect their perception of self-worth (Dube, 2016).

In the long run, widows and widowers suffer from loneliness. Losing a life partner after having shared many years and memories together creates a void (Maphosa & Maphosa, 2014). Often widows and widowers try to fill this void by engaging in different behaviours such as immersing themselves in work, creating new life patterns such as frequent visits to the bar or through remarrying. This comes from the loss of intimacy in the surviving spouse's wife and the absence of a central figure with whom they would have confided with for years on end. The loneliness and lack of intimacy that widows face often places them at the risk of exploitation. The need for intimacy and to counteract loneliness makes widows vulnerable to some men who view them as an easy target for sexual exploitation (Evans, 2015). As such there is often observed difficulty in making and maintaining new relationships.

Most of the rural communities in Sub-Saharan Africa suffer from economic hardships and challenges. With men being seen as the dominant breadwinners, death of the male spouse may entail the dawn of poverty if no proactive solid financial decision had been made to mitigate this. To counteract the effects of poverty, women may remarry even when they are not ready to and subject themselves to the new realities of remarriage (Ogweno, 2010). Some women have reported going into the prostitution trade in an attempt to provide for their children. With little in the form of social organisations, government and non-governmental operatives offering protective services to widows in terms of education and resources, being an HIV infected widow brings hard realities.

## 2.5 Self-identity reconstruction

Overcoming perceptual consistency is a process by which prior beliefs surrounding an interpretation of circumstances that triggered death of a spouse remains cemented and dominant in the surviving spouse despite finding new evidence on what could have brought HIV home (Hermans, 2013). This means that the surviving spouse has to answer questions related to how they got HIV positive and who might have brought the virus to the marriage. The guilt and shame attached to the experience interfere with an identity one develops about who they are and how they are to interact with others (Beech, 2011). Evidence from the study conducted by Beech (2011) further highlights evidence from a study carried out at the University of Andrews on liminality and practices of identity reconstruction which pointed out that self-identity formation remains key to the reconstruction of the self, therefore, understanding the nature and form of beliefs and assumption of what could have killed the spouse are important before one comes to terms with the acknowledgement of permanence of death as a virtue in life.

The process of self-identity reconstruction includes conciliation, disclosing of HIV status and migration towards economic independence, hence, in the case of the surviving HIV positive spouse conciliation and economic independence were perceived as critical factors (Speakman, 2012). However, some women further acknowledged the role they had been identified as, became prostitutes and fended for their wellbeing through sexual activities in defining their reconstructed identity (Mojola, 2014).Self-identity reconstruction influenced individual behaviour through which the individual dialogues the self to acknowledge a radical shift in perspective and reorientation of personal behaviours to positive living (Parish, Laumann & Mojola, 2007). These personal behaviours include the practice of HIV treatment, seeking support from others and consistent healthy and pro-social behaviours (Kleiber et al., 2002). This process is directed towards moving from the perceived spoiled self to the reconstructed self. Building a new self-identity cannot prevent finding a place for HIV positive status within the self in the form of acknowledging and living positively with HIV.

In a study conducted by Platter and Meiring (2006) on the psychological relevance of meaning making, they observed that infected people introspect and dialogue by themselves in an attempt to make sense of how being affected affects their general functionality and, as such, make sense out of their experiences. Acceptance of the status was one of the important aspects that Park and

Folkman (1997) cited by Platter and Meiring (2006) proposed as a means of resolution with the self. Acceptance also allowed the infected spouses to reconcile the stressful experiences and responsibilities they had to face and encounter after losing a loved one (Mojola, 2014). Furthermore, acceptance opened doors for making peace with the self before the individual interacted with others who need their attention. The denial, anger, depression, bargaining and finally acceptance of the chronic condition allowed individuals to develop resilience and build tolerance over diluted and misconceptions negative people had towards the infected (Ross, 2011). However, there are some HIV positive individuals who get stuck at the denial or anger stage and becoming highly suicidal in life.

The transition from spoiled identity to reconstructed self-identity as postulated by Platter and Meiring (2006) found most individuals blaming themselves for their HIV positive status. Some even made conclusions that they deserved the virus and, as such, they had to make peace with the chosen life styles that had caused them to contract the HIV (Platter & Meiring, 2006). The claims of self-deservedness may seem self-diminishing, but Folkman (1997) cited by Platter and Meiring (2006) relayed that such attributions followed by behavioural self-blame (Marteau, 1995 cited by Platter & Meiring, 2006) provided the participants with a sense of control over the cause of their current situation and a foundation for mapping a way forward based on informed choices harnessed from previous experiences as infected individuals. The argument here is that self-blame could be the beginning of acceptance of the HIV positive status that might lead to the development of internal strength to fight stigma and discrimination.

Meiring (2003)'s study of self-blame and personal deservedness in Namibia identified that these two factors combined with participants' belief that their contraction of HIV was a punishment from God made them appreciate life than they did before contracting the virus. Although self-blame (internal attribution) and punishment from God (external attribution) seemed to contradict each other, they help the participants reconcile and deal with the virus. These attributions not only influenced their orientation towards appreciating their health statuses, but rather also provided an element of hope in the future important for development of the reconstructed self (Mojola, 2014).

Increased access to information on HIV to society and those living with the disease has played a fundamental role in self-reconstruction (UNAIDS, 2013). The generalization of HIV as a

personal choice acquired disease has since been replaced by knowledge in regards to its contraction and transmission, (Parish et al., 2007).Identity crisis in individuals living with HIV was attributed to the misunderstanding of the disease even at the field of work, resulting in the firing and social exclusion of these people, therefore, their roles and obligations to society and family were dismissed leaving them without a clue on how to survive.

In an attempt to understand identity development through how people living with HIV dialogue within themselves and self-introspect to challenge rejection, stigmatisation of their identity, researchers assessed their coping mechanisms (Auerbach et al., 2011). They found two prominent approaches that people living with HIV adopted as coping strategies with the first one being stigma avoidance and the second being stigma control (Stangl et al., 2010). Therefore, identity construction in the context of HIV can be conceptualized at a macro level with focus directed towards cultural, political and economic frameworks rather than individuals to enhance capacity building approaches to social transformation and inclusion of individuals with HIV in society (Liamputtong, Haritavorn, & Kiatying-Angsulee, 2009). The reconstruction of identity of people living with HIV should stem from society as a building block in the triggering of a social transformation, thereby laying a foundation for self-dialoging of individuals to accept their roles again in the face of society and their appreciated presence.

Tsarenko and Polonsky (2011), observed that most females reunited with their close relatives and friends compared to males as they underwent the process of identity reconstruction. The availability of information and awareness strategies enhanced the capacity of their loved ones who once rejected them because of their status to acknowledge and accept them once again (Stangl, Carr, Brady, Eckhaus, Claeson & Nyblade, 2010). Furthermore, amongst the males, economic independence created better chances of acceptance by society, however, the monetary value and dominance it brought gave them an upper hand in decision making towards issues that affected their overall life experiences. Most of the participants in Stangl et al.'s (2010) research expressed the intense feeling of wanting to reunite with their families especially after they had achieved a better quality life for themselves. Identity reconstruction remains a vague concept though, individuals who work in urban areas report having reconstructed their self-identity by attaining the best medical facilitation in the country after experiences of rejection by loved ones

(UNAIDS, 2013). Therefore, the intrinsic conversations that cognitively take place are essential in the determination of what constitutes identity reconstruction in people living with HIV.

Smooth transition in identity reconstruction emanated from the means and ways through which one managed and manipulated environmental variables such as stigma and discrimination (De Waal, 2013). De Waal (2013) further acknowledged that identity construction is a combination of all these attributes including experiences on how to manage exposure to outside speculation and negative information directed towards the self (Tsarenko & Polonsky, 2011). The experience of a reconstructed identity is felt if all aspects that were present before the spoiled identity are restored (Whitehead, 2014). If there were missing factors observed by the individual, their reconstructed identity experiences were slightly lower than the constructed identity prior to exposure or contraction of HIV and AIDS. Prior to the achievement of the reconstructed identity, De Waal (2013) argued for a relapse if the environmental factors became overwhelming once more. The achievement of the reconstructed identity is not an assurance of continuity in the attained identity. Therefore, continuous management and controlling of factors that strengthen the reconstructed identity should be capitalized on (LaRocca & Scogin, 2015).

Building on a self-sustaining economic foundation was highlighted as one of the major factors that made HIV infected adults who are either widows or widowers heard in national forums (Tsarenko & Polonsky, 2011). Most prominent figures with a strong economic base made those HIV negative people realize that HIV positivity is merely a chronic condition, but not a degenerative disease that affected brain functioning (Mojola, 2014). Evidence suggested that a steady economic base assured individuals of good health and, as such, boosted their physical appearance which was identified by Elad (2008) as the major factor that impacted negatively on the dialogical self. Therefore, access to better resources allowed for a gradual transition into the reconstructed identity as observed in the ethnographic study conducted by Parish et al. (2007) on implications of HIV on identity amongst the Chinese people.

Improvement on factors that were identified by Whitehead (2006) as crucial for improving the experiences of widows and widowers surviving with HIV proved efficient and effective towards the development of the reconstructed self. The management of stigma and improvement of health status in both male and female participants in the research conducted with the Nepalese resulted in a smooth transition from spoiled identity to reconstructed identity to even become equal to

their statuses prior to contracting HIV (Aryle, 2015).Therefore, in the study, factors such as personal resilience, medical treatment and support mechanisms were identified as very important in the transformation of diluted cognition and perceptions of self-worth that help in building the reconstructed self-identity (Whitehead, 2006).

### 2.6 Experiences of HIV positive married people

Sero-discordance has been one of the several factors that have magnified the experiences of married people surviving with one partner being HIV infected. These partners are sometimes called mixed serostatus (Shapiro & Ray, 2012). The challenge in these types of marriages as observed by Chingwaru and Vidmar (2016) was the investment and attentiveness towards avoidance of infecting the other partner presented by the infected partner as evidenced by some couples in Zimbabwe. This abstracted attention impacts negatively on the eminence of romance and intimate interaction amongst the sero-discordant couple. Petronio (2012), argued that fear of transmission resulted in over exercising of prudence that may trigger stopping of all sexual activities. This has a great impact on the disclosure of partners about their HIV positive statuses.

In a study that was conducted by Man, Kelly, Worth, Frankland, Sihh, Kupu et al. (2013) on sexual risk behaviour, marriage and art in Papua New Guinea, the gathered evidence indicated that where HIV status was disclosed amongst the couples, the use of condoms was negotiated for and this was regarded as intimate partner communication. This was most prevalent amongst women who were HIV positive, they reported use of condoms at the beginning of the diagnosis, but evidently as the relationship continued condom use discontinued (Man et al., 2013). Van Lange and Van Doesum (2015) further argued that such a development in intimate relationships was a result of dialoging in the self of the other partner who as a result develops trust and the need to remove protection in the consummated relationship. The discontinued use of condoms was an effort by the other partner to prove the love that they had, however the decision was most outstanding in the rural areas were knowledge and awareness with regards to HIV and health related consequences was low.

The study conducted by the Center for Disease Control (CDC) (2012) in Zambia also supported by evidence that identified correct and consistence in condom use amongst the urban dwells of Zambia. The findings also identified collaboration amongst sero-discordant couples in trying to improve each other as they lived together. However, Izum (2007) observed that problems

associated with such kind of relations were associated with one partner developing the need to care for the other significantly impacted on the quality of interaction and communication in the intimate relationship. The experiences of care became overstated resulting in reduced intimacy and sexual exploitation amongst the partners in the relationship (Sabin, Desilva, Hamer, Keyi, Yue, Wen & Gill, 2008). Similar experiences of care were observed amongst sero-discordant partner in Kenya, Canada and China (CDC, 2012).

Gender differences in the need for sexual intercourse were varied amongst women and their husbands in Bangkok, Thailand (Bennetts, Shaffer, Manopaiboon, Chaiyakul, Siriwasin, Mock & Clark, 1999). Of the 102 HIV infected women and their husbands, 30% of whom who were negative reported varied desire in engaging in sexual and intimate encounters with their positive spouses. Income manipulation was a factor that most positive individuals whose role in the family was providing for the family. The evidence identified income discrepancies amongst sero-discordant partners as more compared to that in concordant couples. Males living with HIV were observed to portray a manipulative role if they desire unprotected sex with their sexual partners in marriage (Bennetts et al., 1999). Thus, despite their HIV status, men consistently indulged in risky sexual behaviours as compared to the female counter parts.

Paulos (2011) pointed out that intimate experiences are usually good if both individuals are identified HIV positive as compared to sero-discordance. In concordant serostatus the issue was mainly around who brought in the virus, but with both individuals caught in a shared circumstance the implications of marginalizing each other are minimal. Paulos (2011) in the research conducted in Papua New Guinea identified several problems arising as a result of sero-discordance amongst married people. The majority of the interviewed individuals reported that they were not willing to sero-convert their HIV statuses no matter the circumstance and as such some lost total interest in the HIV positive partners (Vandall, Wertheimer & Rahdert, 2012). The orientation of the relationship without sex led to the development of other problems such as lack of interest in communicative behaviours, loss of emotional intimacy and attachment (Izumi, 2007) psychological and sexual torture on the HIV positive partner in sero-discordant couples (Man et al., 2013) and significant decline in intimate attraction and love.

Man et al. (2013) in their study on sexual risk, marriage and ART identified that in New Guinea, the HIV infected reported not having been involved in an intimate relationship six months prior

to their survey. Marital status was the most important trait in determining sexual intercourse indulgence, but the evidence suggested that vaginal sex even with the use of condoms was low. On the other hand, amongst those sero-discordant couples who indulged in vaginal intercourse, condom use was very low with 77% agreeing to reduce condom usage as the relationship matured further (Hughes et al., 2012). The activities were most inclined towards heterosexual intercourse and no reports on homosexual encounters were made (Man et al., 2013).

Furthermore disagreements about the sustenance of sexual life were observed as the most prominent amongst sero-discordant couples as compared to concordant couples (WHO, 2012). These disagreements brought in a lot of stress and tension as was observed in a study reported by Paulos (2011) in New Guinea. The major problem was around having biological children without the actual transmission of the virus among married couples, the feasibility of such was less likely if the female was positive and the male negative (Ware, Wyatt, Haberer, Baeten, Kintu, Psaros, Bangsberg, 2012). However intimate abuse was prone if the male was positive and the female negative, the man would demand sex and need for children as a conjugal right as was observed in the rural parts of New Guinea, Kenya and Tanzania (Paulos, 2011).

The experience of knowledge about having HIV was not a pleasant one as reported by married couples in Man et al.'s (2013) study. The research observed that marriage was centred on having children in the near future and most young couples with HIV faced major decisions to either have or not have children (Briggs, 2012). Paulos (2011) argued that the impact was not that significant amongst concordant couples as was with sero-discordant couples. Low condom use amongst the inhabitants of Papua New Guinea did not reflect their desire to have children, but rather their desire to experience unprotected sex that was amounted to true love (Man et al., 2013).

Gathered evidence indicated a wide array of emotional states that were presented by couples after knowing their statuses (Higgins, Hoffman & Dworkin, 2010). There were differentiated experiences of shame and guilt amongst the couples, and these were observed as emanating from varied sources and causes (Rosenthal & Levy, 2010). The evidence suggested that in Congo, sex and sexual relationships were affected by war and, as such, most individual contracted HIV during the freedom and liberation quest and many got married with a sero-positive status already (Staveteig, Wang, Head, Bradley & Nybro, 2013).

However, in the same Christian society, males were not significantly impacted on by their serostatus (Staveteig et al., 2013). Evidence suggested violence as a coping mechanism that most men took in areas such as Nigeria, Ghana and Senegal, Rosenthal and Levy (2010) also argued that feelings of shame and guilt were present amongst the Sub-Saharan region males whose behaviour became compensatory and presented an over exaggerated kindness towards their spouses in both sero-discordant and concordant marriage relations

**2.7 Knowledge gap**

As far as I have investigated, most studies seem to have paid less attention to the notion of forgiveness in their focus on the reconstruction of a new self. The focus of the research has mainly been on the problems of widowhood and the support systems available for the older widows (Chambers, 1994). There is very little on the widowers. HIV has resulted in many widows and widowers, and many of them are HIV positive. Their personal and subjective requirements have been understudied. There are surviving HIV positive spouses who feel responsible for the death of their partners, and there are those who think that their late spouses are responsible for their being HIV positive. This study attempted to find the role of forgiveness through the dialogical self in the reconstruction of self-identity among the surviving HIV positive spouses. I hoped to find out how the surviving HIV positive spouses have managed to cope with everyday life after the death of their partners.

I was also motivated by the limited availability of literature on the experiences of the spouse before and after the loss of a partner to HIV-related illness in the context of African communal value system. The research observed literature gaps in addressing and differentiating the circumstances that individual pass through both at individual and family level that in turn influence how they deal with losing a partner. The entirety of the experience of life after losing a loved one is undermined by low investment of researchers of their time and resources towards understanding the decision making and implementation in HIV surviving spouses as they try to deal with every day issues adjoining gender, socio-economic and political circumstances and their interaction with sero-positive status.

Furthermore, cases of HIV in the context of rural areas have targeted the spread, epidemiology and lived experiences on the context of HIV, however, they have not further looked at experiences prior to losing a loved one to HIV-related illness and how one would deal with

factors such as disclosure, dealing with self and societal prejudice, self-isolation and development of a spoiled identity influence by segregator community norms. The transition that an individual has to go through to address issues tied to the spoiled self until they develop a reconstructed self that lives in harmony with society. Furthermore, most of the research that has been conducted across the world does not target the experiences of HIV in the context of collectivism and collective decision making that impact the African surviving spouses. The transgression from reporting to the husband, as the centre of authority, to reporting to the whole family and significant others who feel they have a responsibility over the wellbeing of the individual and the surviving children if there are any. Therefore, the complex African setup and family system triggers complication that may hinder or develop the psychological wellbeing of the surviving spouse in the context of African settings in a rural setup. Therefore, the research sort to capture the silent aspects of the lived experiences of surviving spouses, prior to losing their loved one, how the loss impacted on the general function in self and societal created experiences and how they have become who they are because of such experiences.

### 2.8 Chapter Summary

Literature of various researches of the same nature to the current study was reviewed in this chapter. I reviewed the concept of HIV in marriage, the meaning of self, self-identity and what it means to develop a spoiled-self. I further focused on the conceptualisation of what widowhood and widower hood meant to individuals who would have lost their spouses to HIV related illness. I also looked at how HIV positive people reconstruct their self-identities and new selves after testing HIV positive and, finally, I identified the knowledge gap as the missing voices of the surviving HIV positive spouses in many of the researches focusing on HIV

# CHAPTER THREE
# THEORETICAL FRAMEWORK

## 3.1 Introduction

From a psychological point of view, HIV positive status is a period of many questions, self-explorations, and anxious expectations. If you are diagnosed with HIV, your physical health is not the only issue you have to deal with, there are mental health issues to contend with. Along with the physical illness are mental health conditions that may come up such as depression and anxiety (WHO, 2015).People living with HIV often get involved in self-conversations about how, when and where, they might have got infected with HIV and these conversations are subject to many things that may affect their mental health including feelings such as fear, anger, helplessness, sadness and anxiety. In this study, I used Dialogical Self Theory as the main lens with the assistance of Kubler-Ross model to examine and understand the phenomena under investigation. Hermans (2009) sees the dialogical self theory as proposing a far-reaching decentralisation of both the concept of self and the concept of culture. The concept of self represents the internal sources for adaptation to HIV such as cognitive appraisal of the situation, perception of the current life events, self-concept and self-esteem, self-control and self-efficacy and appraisal of the future. The culture represents the external sources for adaptation such as stigma and discrimination where stigma is the attitude and discrimination is the act.

Kubler-Ross (1969) postulates a series of emotions experienced by terminally ill patients prior to death or people who have lost a loved one and the five stages identifiable are: denial, anger, bargaining, depression and acceptance. The meaning that the HIV positive person would construct of the current self is more likely to be influenced by the acquired HIV positive status and the resolution would come from the self-conversations that involve the internal and external sources and issues of denial, anger, bargaining, depression and acceptance are likely also to arise. The dialogical self would involve forgiveness and reconciliation for the adaptation to HIV positive status and self-identity reconstruction. Immediately after the death of one’s partner, the surviving HIV positive spouse begins to engage on self-conversations (dialogical self), the journey of reflection and forward thinking about the future also begins. It is at this stage that

Kubler-Ross' model of five stages kicks in to the surviving HIV positive spouse on the journey to reconstruct a new self.

### 3.2 Theoretical Framework: Dialogical Self

Hermans' (2003) theory of the dialogical self provides a rich and insightful framework for understanding the forgiveness in self-identity reconstruction among the surviving HIV positive spouses. In the extended dialogical self, there is no clear boundary between the inside and the outside of the mind. The self and its contents are radically open and accessible to the world and the various social and cultural voices present therein. A person who is HIV positive does not live alone, his/her status is likely to be known soon or later to significant others and this changes his/her position in relation to his/her significant others as a result of his/her HIV status. The collection of these utterance and perspectives, known individually as "positions", constitutes a decentralised self with many different, relatively autonomous, voices existing within it simultaneously. Hermans (2003) terms the collection of these positions within the self's psychological space a repertoire. Repertoire, although composed of separate autonomous positions, is united by the individual's personal sense of temporal continuity (Hermans (2003). Thus, the multitude of different voices that comprise a given individual are nonetheless experienced as a single continuous consciousness.

Dialogue which occurs among the positions within the self can be understood in terms of exchange and power (Hermans, 2004). Dialogical relations are always more or less asymmetrical with regard to the power vested in one position over another at any given time. However, strong asymmetries in power decrease dialogue between positions and the potential for adaptive innovations. As far as one position silences the voice of another, the self is deprived of the richness and flexibility that comes from a diversity of perspectives. Camlin (2017) observed that the self that is HIV positive (spoiled self) becomes less powerful in its conversation with the external source (culture) that views the 'spoiled self' as having transgressed against the society. The power of organisation of positions in the dialogical self can be more precisely understood in terms of spatial movements (Hermans & Hermans-Konopka, 2010). Progressive or regressive movements refer to the self's ability to understand itself in new, more insightful ways, with regression occurring when the core discourse among positions are disrupted and the individual experiences concomitant tension and ambiguity in self-understanding. In contrast, centralising or

decentralising movements refers to the role of certain positions in defining the self as a coherent whole and in prescribing congruent courses of actions for the self. Decentralising movements occurs when previously core positions are dislodged from their guiding positions and relocated towards the periphery of the self. This, I observed, as the notion that people enter into marriage without the preparation of being a widow or widower and as such its eventuality is unwelcomed. The lack of knowledge about how HIV is transmitted creates vulnerability of HIV positive spouses to stigma and discrimination. The surviving HIV positive spouse remains with many questions to answer and a lot of explanations to make which might lead to feelings of guilt, powerlessness and anger. In case of both regression and decentralisation, the individual is likely to experience significant anxiety and distress as the continuity of their preferred personal discourse is threatened. However, these movements also provide an opportunity for re-organisation of the self if new dialogues can be formed between positions in the self that allow for flexible and constructive responses to the changing environment (Kahn, Preis & Hermans, 2012).

In delineating among voices within a given individual's repertoire, Hermans (2003) uses the distinction of the *'I'* and the *'Me'* as corresponding with internal and external repertoire positions. Internal positions correspond to *'I'* and are those voices serving as the person's sense of self-as-knower. In contrast, external positions correspond to *'Me'* and are those voices appropriated to or belonging to the person in some way. Importantly, external positions include all such relationship of ownership, both positive ("my friend") and negative ("my enemy") and develop whenever an individual meaningfully perceives and engages with another self. Additionally, the dialogical self includes within its repertoire of external positions the collective voices of larger social structures, such as groups, institutions and cultures (Hermans, 2003). As the dialogical self is constituted by relatively autonomous voices, the boundaries between internal and external positions will vary fluidly between and within persons by context, necessitating that any understanding of an individual be grounded in a holistic recognition of the situation under consideration (Hermans, 2003)

The self-identity and being of a surviving HIV positive spouse is heavily distorted. His/her survival for the future depends on the self-development. Self-development is regulated by the processes of construction and reconstruction of meanings which occur in the context of narrating

oneself to others. Each narrative account has external audiences or, as with stories told wordlessly to oneself, internal audiences (Hermans, 2003). However, constructing a self-narrative, that is, a self-told life story by which the singular events narrated come to be articulated, is not simply a matter of organising life events as they occur. In fact, it also entails a process of selection and amalgamation of life experience (McAdams, 1993), since only a small part of the multitude of the person's experiences is incorporated into the self-narrative (White & Epston, 1990). This process of self-narrative construction is dialogical, in the sense that a self-narrative, as Hermans (2003) has clearly shown, is not the result of an omniscient narrator, but the result of the dynamic interplay between the positions of the self, or *'I'* positions, which organise the self at a given moment. These several *'I'* positions may then animate inner and outer dialogues, in which several voices can be heard and give meaning to the current experience. Self-identity reconstructions are the outcomes of dialogical processes of negotiation, tension, disagreement, alliance and so on, between different voices of the self (Hermans, 2003). Tsarenko and Polonsky (2011) argued that there are several debates that go on in the minds of surviving HIV positive spouses as they go through the stages of shock, denial, withdrawal, bargaining and acceptance of their HIV positive statuses. These dialogues would require forgiveness and reconciliation for the successful and resolution in reconstruction of self-identity. According to Tabana et al (2013), it is these voices of the internal sources that would debate with the external sources to strike a balance within dialogical self. These conversations are not easy because they border on lines of accusation, suspicions, loss of trust, fear and anger on who actually brought the HIV home.

### 3.3 Dialogical Self Theory and Forgiveness

What constitutes forgiveness is subjective with differing views on the core concepts around forgiveness. The most basic definition of forgiveness entails agreeing after rumination to move, live and see past perceived transgressions. Forgiveness, to Hargrave and Zasowksi (2014), is a conscious decision to try and terminate feelings of resentment or vengeance towards a person or a group that has directed perceived, either real or imagined, physical, social, psychological and emotional harm. It is an afterthought choice made to cease bitterness and anger for the misgivings committed by another individual on your person. Forgiveness is an act or behaviour that can be expressed overtly, but engaged in internally that has social and psychological connotations and effects particularly for the parties engaged in forgiving. It is the first step

through which the emotions and psychological wounds carved by another begin to heal. The surviving HIV positive spouses need to make self-conversations and debates within the self for them to reach forgiveness for both the self and the deceased partner.

Often the act of forgiveness follows after a person who has wronged another asks the person he or she has transgressed against for forgiveness. However, the social and psychological facets of forgiveness can precede or come after the act. According to Adonis (2015), though a person can claim to have forgiven someone for wrongdoing, true forgiveness only comes after thoughtful deliberation and the cessation of the negative emotions held towards that person for that particular incident. To the person forgiving, forgiveness is a product of an internal conversation that evaluates numerous variables and reaches the conclusion that is forgiving (Chung, 2014). These variables can be termed forgiveness motivators as they drive the person who feels transgressed against to finally overlook the perceived wrongdoings and let go of the hurt and pain.

Forgiveness often follows the committing of a transgression. This transgression may be real or imagined on the part of the victim of the said transgression. Being infected with HIV represents a complex scenario which can be interpreted as a transgression. When individuals enter into a marital agreement or arrangement they often hold expectations. Although these differ from person to person, the most common expectations held include exclusivity, loyalty, honesty and commitment to the marital union. If these expectations are shared and upheld, the chances of being infected with HIV become increasingly minimal. However, failure to uphold them often results in infidelity which leads to infection with HIV. For the partner who does not commit infidelity, being infected with HIV when being in a marital structure that is supposed to protect them from infection, can be explained as a transgression, an act of wrongdoing (Jangu, Tam, & Maticka-Tyndale, 2017).

Similarly, a transgression can be committed against oneself. If one holds beliefs and values closely and expects to commit to those values, when they go against those set of values, they may feel as if they have transgressed against themselves (Peterson & Van Tongeren, 2016). This often results in self-blame and self-hate especially when the said scenario led to undesirable consequences. This is an instance of what some surviving spouses infected with HIV often face. When someone infects another person with HIV even unknowingly, this can present itself as a

challenge to the person who infected the other, especially when they had no prior intention to harm or hurt the victim of the act. When a spouse infects their marital partner as a consequence of infidelity, they may feel as if they have transgressed not only against their partners but themselves. As HIV progresses and the opportunistic infections mount, this feeling may intensify such that at the point of death spouses often feel overwhelmed with guilt for their actions.

Acts of transgression form the foundation on which forgiveness is built upon. Forgiving a spouse for infecting you can be immensely difficult. Especially in instances when the spouse has passed on without asking for forgiveness. This can lead to the opening of a psychological wound and scar, a need for closure. To forgive becomes a struggle since the subject of anger and resentment is not alive to elaborate on his or her actions. An internal conversation, a dialogue with oneself must then be held to get an understanding of the transgression and to find possible reasons why the transgression was performed so as to enable the surviving spouse to grant forgiveness (Bartholomaeus & Strelan, 2016).

The need to grant forgiveness is often motivated by a number of factors. Often it is driven by the desire to give oneself peace of mind (Doolittle, Justice, & Fiellin, 2016). Holding on to hurt, resentment and vengeance can be emotionally and psychologically exhausting. The memory and events that formed the transgression are often painful and recalling them forms a never ending cycle of hurt and pain and this cycle can only be broken through forgiveness, through the decision to terminate any feelings of resentment towards the object of anger (Mugweni, Pearson, & Omar, 2015). This is the reality that faces some of the people who were infected with HIV by their partners. The memory of those persons inflicts pain, anguish and even regret to those whom they infected. Berman (2015) observed that to avoid this pain and emotional feeling of discomfort, the infected person engages in an internal dialogue identifying the source of the emotional pain and the futility of holding on to the painful memories and ideas.

According to Doolittle et al. (2016), often forgiveness may become requisite for a person before they take a major life changing decision which is often related to the subject behind the transgression and the transgressor. Surviving spouses are often faced with the opportunity to remarry. Yet the decision to remarry can be impacted by the past experiences. Following being on the end of contravention, victims often develop a lack of trust for transgressors and anything or anyone remotely resembling the transgression and transgressor. Forgiveness in such instances

becomes an essential step necessary for the widow or widower to take if they are to again fully appreciate the significance and importance of marital unions and have an emotional attachment to the person they had developed repulsion towards.

Sub-Saharan Africa embraces a diversity of religious that prescribe moral behaviour and teachings (Sovran, 2013). There are many religions (Christianity, Islam, African indigenous religions) practised by many sub-Saharan Africans in Africa and wherever they happen to be, with Christianity being the largest religion. Velayati, Bakayev, Bahadori, Tabatabaei, Alaei, Farahbood et al. (2007) argued that cultural norms and values as well as religion define the health-seeking strategies of many Africans. Many authors posit that for a majority of sub-Saharan Africa especially people living with HIV, spirituality has become a label for meaning, values, transcendence, hope and connectedness (Adams & Trinitapoli, 2009). Religious organisations in most regions of Africa are often the key providers of care and support to people living with HIV. Kremer and Ironson (2009) argue that most sub-Saharan African people living with HIV associate better health outcomes including self-confidence, coping, treatment adherence, longevity and coping skills to spirituality and religious involvement. Sovran (2013) further posits that research has shown that religion and spirituality take a central place in the treatment and care of sub-Saharan Africans, in making sense of the illness and coping with HIV. It is further argued by Kremer and Ironson (2009) that negative spirituality is when people living with HIV feel abandoned or punished by a higher power and positive spirituality means people living with HIV who firmly believe God loves and forgives them despite their shortcomings. People living with HIV may adopt negative spiritual or religious beliefs in preference to conventional treatment that may be detrimental to health-seeking behaviours, treatment adherence, survival and quality of life.

The concept of forgiveness in Sub-Saharan African communities is closely related to religion (Jones & Musekura, 2014). Christianity, which is amongst the dominant religions, demands that its followers forgive those who have sinned or transgressed against them. It is precondition that followers must obey as they seek forgiveness for their sins. The concept of forgiveness is engraved in Christian values and is a key element of the predominant prescribed Christian prayer. Those that feel wronged and harbour feelings and thoughts of hurt and resentment towards their transgressors actively do not follow stated Christian principles. To forgive becomes

essential for Christians if they are to align their beliefs and their behaviour. To avoid feelings of cognitive dissonance, Christian followers have to forgive any said transgression. An internal conversation follows where the individual analyses their thoughts, feelings and behaviours and aligns them to their dominant beliefs.

The decision to forgive often follows after the observation of perverse influences of resentment on personal life (Peterson & Van Tongeren, 2016). Often, feelings of resentment can influence a person's outlook on life by increasing the frequency of negative affect. This lowers positive perceptions and increases negative emotions like anger, sadness and regret as well as the overwhelming need for vengeance. These have the ability to influence observable behaviour latently. Persons who hold anger against their spouse can inadvertently direct this anger and hatred towards their children leading to failure to adequately cater for the needs of these children. Observing such tendencies can facilitate the need for forgiveness for the greater good of the welfare of concerned children.

Forgiveness can be done to help build a good mental picture and memory of the deceased. Though the deceased might have committed huge transgressions against the surviving spouse, they still remained a central figure in their lives. The memory of the transgression may become dominant and undermine the other qualities and memories that the deceased and the surviving spouse may have shared. The need to balance memories often makes it worthwhile to forgive especially as positive memories of the deceased begin to surface over time. Often forgiveness is a natural process that happens automatically over time. The significance of the committed transgression becomes lesser and lesser over time. As the infected person gets older, the significance of being infected by a loved one lessens, especially when there are no seemingly evident consequences of infection (Jilani, Chang, Yu, & Lin, 2015). For instance when the surviving spouses remains free of opportunistic infections that may threaten death. When the transgression loses its value, it then becomes easier and simpler for the surviving spouse to forgive the deceased for his or her transgressions. This usually occurs over time when the perception of transgression pertinence changes which leads to the surviving spouse to decide to end any ill feelings previously held for the deceased.

Mills (2017) shares insight into the forgiving process of a woman who had been infected by her husband. The husband, named Barry, had contracted HIV through infidelity while working in

another country in the merchant navy. The infection was identified 15 years later when Barry fell ill after which he was forced to confess the extra marital sexual encounter he had shared in the past. The decision to forgive for Veritee, Barry's wife, was complex but simple. Instead of blaming him and being bitter for being infected, she blamed him for infidelity. She then justified his infidelity by stating that it was the norm in their community and that it was reasonable and most probably going to happen since Barry was working away from home for eight months out of the year. She also interpreted his decision not to tell her, at the time, of his infidelity as a sign that he was very affectionate towards her and did not want to lose her. Veritee underwent one of the most common means of forgiving someone for infecting them, which is through rationalisation of the events that led to the infection and claims to be at peace with being infected though the stigma and discrimination from relatives and neighbours often gets to her.

Self-hate and self-loathing are intricate behaviours for the HIV infected that often lead to self-harm that often require self-forgiveness (Redfern, Barnes, & Chang, 2016). When one believes that his or her behaviour has led to negative consequences for innocent people, they often engage in self-hate and self-accusation for the negative outcomes. Self-forgiveness might not justify or condone the act performed, but it allows the perpetrator to live free of the overwhelming feeling of guilt on their conscience.

Regalia and Pelucchi (2014) highlight that the concept of forgiveness is often not understood clearly by participants in research. They highlight that often individuals mistake accepting transgression for forgiveness partly because the two have similar emotional and psychological impacts of liberating from an emotional weight. A person who has accepted that they have been infected with HIV can live life fruitfully, make informed better choices with regards to their health and future. Because they now live life positively and with optimism, this often tends to overshadow feelings of bitterness towards the person who infected them. However these feelings remain subliminal and as such any research looking into the subject of research should counteract this effect.

Forgiveness has numerous immense benefits which have the potential to increase life enjoyment and prolong the life of surviving spouses infected with HIV. Research by Peterson and Van Tongeren (2016) revealed that forgiveness helped individuals form healthier relationships as well as having a reduction in remorse and self-condemnation. The removal of bitterness enabled them

to look at other people positively and not to judge them from the actions of another. They also reported reduced stress, anxiety, hostility and depression. Research by Bartholomaeus and Strelan (2016) has also revealed that forgiveness has positive impacts towards an individual's self-esteem.

### 3.4 Dialogical Self Theory and Reconciliation

The dialogical self is a constant construction of individuality and persona through continuously interacting with the self. The self becomes a concept by which individuals understand their individuality through a cross examination of the emotional, cognitive and behavioural development in the context of thyself and that of others. Hermans (2004) observed that the dialogical self consists of differing internal voices that require reconciliation for stability and progress of the self.

Reconciliation is an act that comes after a series of consistent dialoging between and within individuals on a particular subject of interest (Alicke, Dunning & Krueger 2005; Balswick, King & Reimer, 2016). It emerges as an outcome of critical evaluation on feelings of worthy invested in individuality and self-identity. Therefore, emotions and behaviours attached to how we deal with internal dialogues about life and establishing our own space in the world are an outcome of conflict within ourselves, the rejection by our being to compromise and reconcile with reality the self is exposed to (Hareb, 2011). Hareb (2011) identified Mandela as a figure that managed to transcend and live in harmony with his self, the entire universe and the existence of others with their varied opinions and perspectives. Mandela's son died of HIV in 2005 and, with his popularity, managed to disclose it at such at a period when death due to HIV of a family member could harness stigma and discrimination directed towards the whole family unit (Hareb, 2011). The nature of being truthful to the self and being aware of how others interpret reality differently from the self allows development and personal growth that consequently promotes reconciliation with the self.

Ross (2011) identified five stages through which individuals go through as they deal with existential issues that impact negatively on individuals' wellbeing and present themselves as life threatening. In her studies on grief and grieving in trying to understand the meaning of death, she identified that the existential crisis in the form of death or chronic illness was not readily accepted and, as such, individuals went through a series of stages before accepting or reconciling

with reality, significant others and the self (Ross, 2014; 2011). Acceptance and reconciliation was a product of dialogue between the self, as one assessed his/her contributions to the existential crisis for example death of a spouse due to HIV. 43% of studies conducted across the USA, Russia and England identified people developing psychological stress and severe depression upon the death of a spouse and especially pronounced HIV related death (UNAIDS, 2013; WHO, 2015). Baingana, Thomas & Comblain (2005) argued that in Kenya the causal-effect relationship could not be established and as such evidence of this nature remained subject to criticism. However counselling services of males in rural Uganda reported that the majority of the clientele that came through referees to seek psychological support after loss of a loved one to HIV-related illness signaled self-blame and self-criticism and felt responsible over the death of a loved one (Bwambale, Ssali, Byaruhanga, Kalyango, & Karamagi, 2008).

Denial was identified as the first step in dealing with HIV related death (Ross, 2011). It not only manifested as a defense mechanism against external criticism, but rather at individual level, denial was experienced as the individual tried to suppress the possibility of them having HIV (Ross, 2014; 2011). Denial triggered motivated forgetting and perceived optimism within the involved surviving spouse as was reported in a qualitative study that was conducted in Swaziland, Namibia, Kenya, South-East Nigeria, Burkina Faso and Senegal (Winskell, Hill & Obyerodhyambo, 2011). Such a destructive approach, according to Tenkorang, Adjei and Gyimah (2010), found that 63% of young adults in the sub-Saharan region and some part of Ghana further indulged in unprotected sexual encounters after losing a loved one to HIV-related illness. The majority emphasized the issue of death on opportunistic infections that deliver the final blow to death and ignored the aspect of HIV as a significant contributor to the ill-health. Reconciliation through self-dialoging ignited certain aspects of recognition of the problem, however, 23% of young adults could not acknowledge this in South Africa (Zhou, 2011; Sanni, 2015).

D'Souza (2011) argued that the issue is not denial of the existence of HIV as a cause of death to the spouse. The central issue was identified as how relationships with the significant others would emerge after the death of a spouse due to HIV-related illness (D'Souza, 2011; Zakaras, et al., 2017). The level of uncertainty and uneasiness of how HIV initially got to the family magnifies the impact of the disease on the surviving spouse. D'Souza (2011) supported Sanni

(2015) by articulating that the level of blame and hate associated with HIV triggered feelings of unworthiness and self-discrimination as individuals constantly evaluate themselves in interaction with significant others. Flint and Payne (2013) identified that due to denial, in South Africa young adults and the older living with HIV and AIDS attributed the death of a spouse to witch craft. This approach made them feel at ease with the self and helped them cope with the day to day demands of the self and society. Such misconceptions in the transmission of HIV and AIDS amongst individuals saved them from blame from the significant others and society, but interfered with their health seeking behaviours (Flint & Payne, 2013).Denial, therefore, serves as a barricade through which individuals continue to survive and make new relations with people who are unaware of the health statuses (Ekstrand et al., 2012). The struggle in reconciliation with the self and others remains entwined with feelings of worthy and the magnitude of self-blame one develops towards the self; this was identified in most individuals that participated in studies that were done by Karamouzian et al. (2015) in Kerman, Iran.

The most prominent aspect of living with HIV contracted in matrimonial relationship was anger. Most people in the study conducted by Flint and Payne (2011) in South Africa recognized a development in temper towards the self and others for letting them down. Such was more pronounced amongst the female participants who reported contracting the disease from their husbands (Friedman & Rossi, 2011; Karamouzian et al., 2015; WHO, 2015). Anger within these individuals was dialogically constructed from a series of self-criticisms and feelings of ignorance towards how they could not see and prevent such (Friedman and Rossi, 2011). The masking effects of denial and isolation wear out triggering the re-emergence of reality and its pain (Karamouzian et al., 2015). The existential knowledge of imminent death and lifelong medication impedes daily functionality. Thus, may be worsened by the perceived mode through which HIV was contracted and the circumstances that championed it. According to Friedman and Rossi (2011) emotions of rage, fear and anxiety develop simultaneously triggering anger as a defense mechanism. This anger targets intimate objects such as children, family members, relatives, and friends and even strangers.

The intense emotion attached to the anger plays a fundamental therapeutic role in dealing with self-awareness of HIV in one's self. Logically the deceased cannot be blamed and made to understand the pain they would have caused, however, the surviving spouse may develop anger

stemming from why they were to be left behind and exposed of their HIV status assuming negative implications of stigma and discrimination (Matiba & Mokgatle, 2016). The anger triggers feelings of guilt and shame which make the individual involved angrier at the self and others involved. Anger amongst the spouses is experienced differently as proposed by Iyer, Schmader, and Lickel (2007). Turan, Hatcher, Medema-Wijnveen, Onono, Miller, Bukusi & Cohen, (2012) further articulated that individuals born with HIV and got married, disclosed their status did not significantly feel the impact of HIV related stigma, but rather their anger stemmed from loss of a loved one and the need to cope with the perception that they were behind the death of a loved one. Friedman and Rossi (2011), however, argued that some people are just angry because they were infected unknowingly, however, upon marriage and intimacy they infected their loved ones and subsequently the loved one passed away. The feeling of why they were not the first to die haunts their individuality and constantly interferes with day to day normal life as highlighted in their study on HIV and AIDS amongst young adults in South Africa (Matiba & Mokgatle, 2016).

Bargaining was observed by Ross as a complimentary stage after the feeling of anger (Ross, 2014). The process is characterised by individualized questions that target the self in dialogue. Questions like, how did this come by, how did I not prevent my loved one from death, how will I handle the affairs of the children and who amongst family members will support me now, stream unconsciously and consciously (Hareb, 2011).The need to regain control marks the beginning of an effort to reconcile with the self (Ross, 2011). The surviving spouse in self-dialogue becomes aware of their vulnerability and feeling of helplessness that trapped their overall functioning making them susceptible to environmental negative comments (Hareb, 2011). Surviving spouses tend not blame themselves over the death of their partners by transferring the cause of death to exterior cause independent of them. They try and figure out possible outcomes if they had visited a doctor early, sort second opinion from another doctor or if they had tried to be a better lover to their spouses (Ross, 2014; 2011a).

Bargaining shifts attention from the experiences attached to the painful realities of losing a loved one (Ross, 2014; 2011a; 2011b). The shift in attention and criticism directed towards the self help the surviving spouse re-focus and concentrate on the present and map a way forward. However (Hareb, 2011) argued that this is only possible if the family members and other social

support systems are helpful enough to provide the necessary supporting structures. On the contrary, Baltazar (2014) observed detachment from family and social systems as a necessary first step towards building a better self and means to suppressing feelings of unworthy and too much self-criticisms generated by the self in dialogue. A report by Hareb (2011) on women issues of domestic violence and HIV contraction proposed that developing good relations with the self-emanate from erasing of memories of violence, sorrow and oppression experienced during intimate relations with the deceased spouse, this becomes the point through which reconciliation develops.

In the context of Africans, spiritual transformation is required to facilitate bargaining (Schonwette, 2016). Schonwette (2016) further argues that through a well-informed awareness of the true contents of individuality and surviving with the reality of HIV positive statuses can individuals activate that content of the self into self-expression. Friedman and Rossi (2011) articulated that through the dialogical self, an individual can have multiple voices that interact to control the observable behaviours, hence, the multiple voices real or imagined that are embodied as one person have a significant influence on how one becomes who they are and how they want to be perceived. These multiple voices are responsible for self-pity and efficacy (Hermans & Hermans-Konopka, 2010), self-worthy (Salgado & Hermans, 2009), self-esteem (Hermans, 2013). Coherence on self-criticism by these multiple voices cement the overall emotional, psychological and behavioural performance of the individual involved. Therefore, the dialogical self is at the centred of how individual self-transform spiritual in the context of Africa traditional values (Gallart, 2017), emotionally, behaviourally and cognitively in the context of postmodern cultural values (Schonwette, 2016).

According to (Friedman & Rossi, 2011) the influence of the dialogical self is observed in its ability to stimulate depressive symptoms in the surviving spouse. In this instance, the dialogical self-act are the collective voices stemming from the *'I'* and *'me'* part of the self (Hermans, 2013). These collective voices have the capacity to constrain the meanings that may be derived from a dialogue between the person and others because it makes use of the rules particularly observed in a shared discourse. This gives the self an ability to objectively assess the situation within which the surviving spouse may be going through as if another individual is doing so (Gallart, 2017). This becomes a reflective interaction between the surviving spouse and the

collective voices through which the implications lead to depressive symptomatology if the collective voices impact hard on the individualised and customized experiences (Gallart, 2017).

The depressive symptoms that stem from the dialogical self are a product of beliefs, assumptions, values and even norms through which an individual was raised from as was the case of widows surviving with HIV in South Africa (Iyer et al., 2007). In an interaction with other community members, the surviving HIV positive spouse engages in an interaction with the self that facilitates a conceptual development of anticipated responses that community members may have. This dialogical self-conversing impact on interpretation of responses the spouse will have in a normal conversation and influences his or her psychological functioning and wellbeing (O'Sullivan-Lago & de Abreu, 2010). These premeditated interpretations trigger feeling of being undermined and consequently affects relations between the surviving spouse and other members in the family unit, relatives and community (Pawelczyk, 2013).

Accepting the other spouse as the cause of the death of a loved one, or living with the chronic illness marks the end of contradictory behaviour in the dialogical self (Eaves et al, 2015). People who accept their statuses do not necessarily give up on their capacities to perform but rather signal an appraisal of life with the inevitability of death. The acceptance of the condition allows one to divert the negative energy towards the construction of positive relations with individuals in their communities and those within the house hold and family unit (O'Sullivan-Lago & de Abreu, 2010). Self-blame and blaming of others become secondary issues and life becomes centred on positive reconstruction of the self. The individual will reconcile with their self-prior to contraction and losing a loved one (Pawelczyk, 2013).

Other authors such as Karamouzian et al. (2015) proposed that acceptance of one’s HIV status played a critical role in allowing plans for the future to evolve. The acceptance allows the surviving spouse an opportunity to mourn and exhaust negative emotions attached to the loss of a loved one (Hareb, 2011). This also comes with accepting the inevitability of blame from those of relation from the deceased’s side, with blame and negative talk directed towards the surviving spouse as the cause of the death (Pawelczyk, 2013). Acknowledging the possibilities of all these existential issues gives the surviving spouse an element of open mindedness which is critical in establishing of peace of mind (Karamouzian et al, 2015). The experience of loss and acceptance is singular and, as such, no one walks the surviving spouse through it, however, dialogues within

the self-help the development of resilience and resistance to emotional breakdowns and self-oriented tolerance to environmental stress stimulating elements (Hareb, 2011). Strength and will to survive rejuvenated through the dialogical self becomes a foundation towards reconciliation within the self and others around.

### 3.5 Chapter Summary

In this chapter, I presented the dialogical self theory as a theoretical framework for the mutual inclusion of self and culture, where individuals are involved in self-conversations to understand their past, current and possible future selves after testing HIV positive and losing their partners to HIV related illness. I discussed the theory in relation to forgiveness and reconciliation for the surviving HIV positive spouses. In the dialogical self, one realises that forgiveness is a process through recognising that life is messy and unpredictable and requires empathy and compassion. Within the same argument of dialogical self theory, reconciliation requires the restoration of fractured relationships by overcoming grief, pain and anger of being HIV positive and this would need acknowledging and dealing with the past, building positive relationships, facilitating significant cultural and attitudinal change in reframing of identity and self-identity reconstruction.

# CHAPTER FOUR

# METHODOLOGY

## 4.1Introduction

Within contemporary psychology, those who wish to investigate the person's grasp of their world in detail will tend to turn to qualitative methods. A concentration on human experience as the central topic of psychology or a focus on construction or interpretation seems to lead, for us, almost inevitably to qualitative research. Smith (2008) asserts that individuals are very active in their perceiving, they search, they pay attention selectively, they make choices, and their perception always has a meaning which is related to their life world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings that people bring to them.

In this research, phenomenological research design provided the theoretical framework for conducting qualitative research within a dialogical self—constructivist paradigm. A dialogical self—constructivist paradigm assumes the existence of multiple realities, in which the participant and researcher are co-creators of understanding in the natural world. To address my research questions within this epistemological framework, the experiences of individuals were examined in relation to their social context and the meanings the individuals themselves attach to those experiences. Smith (2008) observes that, according to narrative theory, we are born into a storied world, and we live our lives through the creation and exchange of narratives as we face any phenomenon in life. A narrative can be defined as an organised interpretation of a sequence of events. Gardner-Neblett and Iruka (2015) identified narrative as an account with three components: a beginning, middle and an end. Freeman (1993) asserts that narratives of a phenomenon not only bring order and meaning to our everyday life but also reflexivity; and provide structure to our very sense of selfhood. We tell stories about our lives to ourselves (dialogical self) and to others. Participants recognise themselves in the stories they tell about themselves. We can hold a variety of narrative identities, each which is connected to different social relationships. Each narrative identity of any phenomenon not only connects us to a set of social relationships, but also provides us with a sense of localised coherence and stability.

It is through narratives of our being (surviving HIV positive spouse) that we begin to define ourselves, to clarify the continuity in our lives and to convey this to others. Narrative enables us to describe our experiences and to define ourselves. In constructing a personal narrative of being HIV positive (a phenomenon) we are selecting certain aspects of our lives and connecting them with others. Hence, Smith (2008) says, this process enables us to assert that our lives are not a disconnected sequence of events but have a certain order. Murray (1997) observes that narrative accounts are not emitted in a vacuum; rather, they are encouraged and shaped by a certain social context. The narrator is an active agent who is part of a social world. Through narrative of a phenomenon (being a surviving HIV positive spouse) the agent engages with the world. Through Interpretive Phenomenological Analysis (IPA), we can begin to understand both the narrators and their worlds.

Within the dialogical self-constructivist framework, identity theorists such as Oyserman and Desti (2010) define identity as the expression of the roles and narratives that people use to express their self to themselves and others. Dialogical self-constructivism directs the narratives of the social person termed the "self" as the key conceptual variable in the explanation of social behaviour. Thus, qualitative methodologies, primarily, in-depth semi-structured interviews, were grounded in the afore-mentioned assumptions regarding the self as a social actor in identity formation, the socially, experientially and situational constructed nature of meanings, and the individual as the primary creator of (their) reality. Constructivists maintain that social reality is a product of processes through which human beings make sense of their everyday actions and situations (Blaikie, 2011). Further, constructivists maintain that to understand human action researchers must understand the meaning inherent in those actions. The meaning of the actions is constructed from the context and through language (Schwandt, 2000). Therefore the research that uses the constructivist paradigm studies phenomena by investigating how people use language and symbols to construct their social reality (Klenke, 2008). Constructivists take a relativist ontological position and a subjectivist epistemological position (Lincoln et al., 2011). Further constructivists argue that research is value laden (Teddlie & Tashakkori, 2009) and that it is impossible to ignore the moral, cultural and political values involved (Walter, 2010).

## 4.2 Interpretive Qualitative Paradigm

Whether we are aware of it or not, we always bring certain beliefs and philosophical assumptions to our research. Sometimes these are deeply embedded views about the types of problems that we need to study, what research questions to ask, or how we go about gathering data. These philosophical assumptions inform our choice of theories that guide our research. Theories are more evident in our qualitative studies. Qualitative researchers have underscored the importance of not only understanding the beliefs and theories that inform our research, but also actively writing about them in our studies. I also believe that I brought with me, my understanding of HIV issues and how they affect individuals and the world in general, hence, in my interpretation I tried not to lean on my only personal understanding but to stand guided by the dialogical self theory.

Philosophical assumptions have been articulated by Denzin & Lincoln (2011, 2005, 2000, & 1994) as the axiomatic issues and guiding philosophy behind qualitative research. These philosophical assumptions have been called paradigms (Lincoln, Lynham, & Guba, 2011; Mertens, 2010); philosophical assumptions, epistemologies, and ontologies (Crotty, 1998); broadly conceived research methodologies (Neuman, 2000); and alternative knowledge claims (Creswell, 2009). They are beliefs about ontology (the nature of reality), epistemology (what counts as knowledge and how knowledge claims are justified), axiology (the role of values in research) and methodology (the process of research). Therefore, as I listened to the stories I stood guided by the theories and the narrators as I tried to decipher what could be the meanings of the told stories.

The ontological issue relates to the nature of reality and its characteristics. When researchers conduct qualitative research, they are embracing the idea of multiple realities. Different researchers embrace different realities, as do the individuals being studied (Charmaz, 2006) and the readers of a qualitative study. When studying individuals, qualitative researchers conduct a study with the intent of reporting these multiple realities. The evidence of multiple realities includes the use of multiple forms of evidence in themes using the actual words of different individuals and presenting different perspectives. Here I tried to capture as much as possible what the participants were narrating verbatim, inclusive of their gestures and the tone of voice.

With the epistemological assumption, conducting a qualitative study means that researchers try to get as close as possible to the participants being studied. Therefore, subjective evidence is assembled based on individual views. This is how knowledge is known, through the subjective experiences of people. It becomes important, then, to conduct studies in the field, where the participants live and work, these are important contexts for understanding what the participants are saying. The longer researchers stay in the field or get to know the participants, the more they know what they know from firsthand information. In short, the researcher tries to minimise the distance or objective separateness (Guba & Lincoln, 1988) between him or her and those being researched.

The procedures of qualitative research, or its methodology, are characterised as inductive or emerging, and shaped by the researcher's experience in collecting and analysing the data. The logic that the qualitative researcher follows is inductive, from the ground up, rather than handed down entirely from a theory or from the perspectives of the inquirer. Sometimes the research questions change in the middle of the study to reflect better the types of questions needed to understand the research problem. In response, the data collection strategy, planned before the study, needs to be modified to accompany the new questions. During the data analysis, the researcher follows a path of analysing the data to develop an increasingly detailed knowledge of the topic being studied.

In social construction, individuals seek understanding of the world in which they live and work. They develop subjective meanings of their experiences, meanings directed towards certain objects. These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrow the meanings into a few categories. The goal of research, then, is to rely as much as possible on the participants' views of the situation. Often these subjective meanings are negotiated socially and historically. I made sure that participants were free to express themselves by reducing the frequency of interjections and writing down what they were narrating as I kept the audio-tapes on.

The participants can construct the meaning of a situation, a meaning typically forged in interactions with other people (Charmaz, 2006). The more open-ended the questioning, the better, as the researcher listens carefully to what people say or do in their life setting. Thus, constructivist researchers often address the processes of interaction among individuals.

Researchers recognise that their own background shapes their interpretation, and they position themselves in the research to acknowledge how their interpretation flows from their own personal, cultural, and historical experiences. Thus, the researchers make an interpretation of what they find, an interpretation shaped by their own experiences and background. The researcher's intent, then, is to make sense of the meanings others have about the world. This is why qualitative research is often called the interpretive paradigm. The term paradigm has been understood differently by various scholars. MacNaughton, Rolfe, and Siraj-Blatchford (2001) explain that a research paradigm comprises three elements: a belief about the nature of knowledge, a methodology and criteria for validity, whereas, Neuman (2000) and Creswell (2003) refer to the paradigm as: epistemology or ontology, or even research methodology. In this current research, I tried to understand the experiences of surviving HIV positive spouses. Creswell (2003), Yanow and Schwartz-Shea (2011), claim that interpretivist researchers discover reality through participants' views and experiences.

The interpretive paradigm allows researchers to view the world through the perceptions and experiences of the participants. In seeking answers to research questions, the investigator who follows the interpretive paradigm uses those experiences to construct and interpret his/her understanding from gathered data. My study explored and tracked the experiences of the surviving HIV positive spouses as they construct their new identities. According to Willis (2007), interpretivism usually seeks to understand a particular context, and the core belief of the interpretive paradigm is that reality is socially constructed. This means that the surviving HIV positive spouses re-construct their identities according to their cultures and societies. Willis (2007) goes on to indicate that different people and different groups have different perceptions of the world. The acceptance of multiple perspectives in interpretivism often leads to a more comprehensive understanding of the situation (Morehouse, 2011).

Interpretive research is more subjective than objective. Willis (2007) argues that the goal of interpretivism is to value subjectivity, and interpretivists eschew the idea that objective research on human behaviour is possible. Smith (1993) believes that interpretivists are anti-foundationalists, because there is no particular right or correct path to knowledge, no special method that automatically leads to intellectual progress. Proponents of interpretivism do not accept the existence of universal standards for research; instead the standards guiding research

are products of a particular group or culture. Interpretive researchers do not seek the answers for their studies in rigid ways. Instead, they approach the reality from subjects, typically from people who own their experiences and are of a particular group or culture.

Researchers believe that the interpretivist paradigm predominantly uses qualitative methods (Nind & Todd, 2011). Qualitative approaches often give rich reports that are necessary for interpretivists to fully understand contexts. Thomas (2003) maintains that qualitative methods are usually supported by interpretivists, because the interpretive paradigm portrays a world in which reality is socially constructed, complex and ever changing. Interpretivists seek methods that enable them to understand in depth the relationship of human beings to their environment and the part those people play in creating the social fabric of which they are a part (McQueen, 2002). Interpretivists do not prefer using the methods that offer objective or precise information. Instead, according to McQueen (2002), interpretivists view the world through a series of individual eyes, and choose participants who have their own interpretations of reality to encompass the worldview. Creswell (2009) states that qualitative research is a means for exploring and understanding the meaning individuals or groups ascribe to a social or human phenomenon. In this study, the social phenomenon of being a widow or widower and being HIV positive were looked at from the participants' view-points. The new world and identities that the surviving HIV positive spouses create would be explored through the dialogical self-constructivist frame.

### 4.3 Phenomenological research design

Phenomenology is an approach to qualitative research that focuses on the commonality of a lived experience within a particular group (surviving HIV positive spouses). Through this process the researcher may construct the universal meaning of the event, situation or experience and arrive at a more profound understanding of the phenomenon. Phenomenology can be defined as an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, & Varpio, 2015). The goal of phenomenology is to describe the meaning of this experience, both in terms of what was experienced and how it was experienced (Teherani, et al., 2015). This means that the voices of surviving HIV positive spouses should be captured and be heard as lived experiences. There are different kinds of phenomenology, each rooted in different

ways of conceiving what and how of human experience. In other words, each approach of phenomenology is rooted in different school of philosophy. To choose a phenomenological research methodology requires the researcher to reflect on the philosophy they embrace. In this study I chose hermeneutic phenomenology because of its interpretive nature which is in line with interpretive qualitative paradigm adopted in this study. The table below illustrate the key defining features of hermeneutic phenomenology.

**Table 4.1: Hermeneutic (Interpretive) Phenomenology**

| **Defining Terms** | **Hermeneutic (Interpretive) Phenomenology** |
|---|---|
| Philosophical origins | Heidegger (1889-1976) |
| Ontological assumptions | Lived experience is an interpretive process situated in an individual's life-world |
| Epistemological assumptions | Observer is part of the world and not bias free; Understands phenomenon by interpretive means |
| Researcher role in data collection | Reflects on essential themes of participant experience with the phenomenon while simultaneously reflecting on own experience |
| Researcher role in data analysis/writing | Iteractive cycles of capturing and writing reflections towards a robust and nuanced analysis; consider how the data (or parts) contributed to evolving understanding of the phenomena (whole) |
| Methodological texts | Van Manen (1997) |

Hermeneutic (interpretive) phenomenology originates from the work of Martin Heidegger. Heidegger was interested in the nature of being and temporality that is an ontological focus (Reiners, 2012). With this focus on human experience and how it is lived, hermeneutic phenomenology moves away from Husserl's focus on 'acts of attending, perceiving, recalling and thinking about the world (Laverty, 2003) and on human beings as knowers of phenomenon. In contrast, Heidegger is interested in human beings as actors in the world and so focuses on the relationship between an individual and his/her life-world. Heidegger's term life-world referred to the idea that individuals' realities are invariably influenced by the world in which they live (Lopez & Willis, 2004). It is this world that the surviving HIV positive spouses create through

self-conversations (dialogical self) as they try to understand what has happened to them ( that is losing their loved ones to HIV-related illness and them living with HIV) or is created for them by the community which is hostile to the surviving HIV positive spouses through stigma and discrimination.

Given this orientation, individuals are understood as always already having an understanding of themselves within the world, even if they are not constantly, explicitly and consciously aware of that understanding (Staiti, 2012). For Heidegger an individual's conscious experience of a phenomenon is not separate from the world, nor from the individual's personal history. Consciousness is, instead, a formation of historically lived experiences including a person's individual history and the culture in which he/she was raised (Lopez & Willis, 2004). An individual cannot step out of his/her life-world. Humans cannot experience a phenomenon without referring back to their background understandings. Tracking of self-identity reconstruction among the surviving HIV positive spouses would entail checking their background going far back at their lives before marriage. Hermeneutic phenomenology, then, seeks to understand the deeper layers of human experience that lay obscured beneath surface awareness and how the individual's life-world, or the world as he/she pre-reflectively experiences it, influences this experience (Bynum & Varpio, 2018). Hermeneutic phenomenology studies individuals' narratives to understand what those individuals experience in their daily lives and in their life-worlds (what is it like to live with HIV).

Hermeneutic phenomenology is rooted in interpretation, interpreting experiences and phenomena via the individual's life-world. If all human experience is informed by the individual's life-world, and if all experiences must be interpreted through that background, hermeneutic phenomenology must go beyond description of the phenomenon, to the interpretation of the phenomenon. The researcher must be aware of the influence of the individual's background and account for the influences they exert on the individual's experience of being. This is not to say that the individual's subjective experience, which is inextricably linked with social, cultural, and political contexts, is pre-determined. Heidegger argued that individuals have situated freedom (Bynum & Varpio, 2018). Situated freedom is a concept that asserts that individuals are free to make choices, but their freedom is not absolute; it is circumscribed by the specific conditions of their daily lives (Lopez & Willis, 2004). Hermeneutic phenomenology studies the meanings of

an individual's being in the world, as their experience is interpreted through his/her life-world, and how these meanings and interpretations influence the choices that the individual makes (Laverty, 2003). This focus requires the hermeneutic phenomenologist to interpret the narratives provided by research participants in relation to their individual contexts in order to illuminate the fundamental structures of participants' understanding of being and how that shaped the decisions made by the individual (Bynum & Varpio, 2018).

Another key aspect that distinguishes hermeneutic phenomenology is the role of the researcher in the inquiry. Instead of bracketing off the researcher's subjective perspective, hermeneutic phenomenology recognizes that the researcher, like the research participant, cannot be rid of her/his life-world. Instead, the researcher's past experiences and knowledge are valuable guides to the inquiry. It is the researcher's education and knowledge base that led to him/her to consider a phenomenon worthy of investigation. To ask the researcher to take an unbiased approach to the data is inconsistent with hermeneutic phenomenology's philosophical roots. Instead, researchers working from this tradition should openly acknowledge their preconceptions, and reflect on how their subjectivity is part of the analysis (Moran, 2000). The interpretive work of hermeneutic phenomenology is not bound to a single set of rule-bound analytical techniques; instead, it is an interpretive process involving the interplay of multiple analysis activities.

### 4.4 Location of the study and target population

Gwanda South Constituency is found in Gwanda District in Matabeleland South Province in Zimbabwe. It is a rural constituency comprising mainly of the Ndebele tribe of Zimbabwe. There is a Thusanang HIV and AIDS Project that works with Manama Mission Hospital in the fight against HIV pandemic. Manama Mission Hospital acts as a District Hospital for Gwanda South Constituency. Thusanang HIV and AIDS Project was initiated in 1993 with funding from the Church of Sweden as a programme of the Evangelical Lutheran Church in Zimbabwe Western Diocese. Thusanang Project envisions a society that is free of HIV and AIDS, through its commitment to capacity building for its membership, partners, local communities, and People living with HIV, through motivating them to respond positively towards the pandemic. Thusanang Project seeks to lobby and motivate individuals, communities and other stakeholders to work together in the face of HIV and AIDS and other adversities. The Project covers two neighbouring districts of Gwanda and BeitBridge in Matabeleland South Province. Thusanang

Project focuses on three thematic areas which are: Home Based Care (HBC); Care of Orphan and Vulnerable Children (OVC); and Information, Education and Communication (IEC) about HIV.

Thusanang Project does management of HIV and AIDS through Home-Based and Palliative Care is done in a consultative, inclusive and holistic way. Communities have been capacitated in the caring and support for chronically and terminally ill clients, through training community volunteers on HIV and AIDS Management, and basic HBC concepts. The project has also advocated for attitudes acceptance regarding People living with HIV among community members with the view of reducing HIV and AIDS related stigma, shame, denial and discrimination. Through community volunteers (caregivers), and in partnership with relevant stakeholders including AIDS Service organisations, the Church (ELCZ and other denominations), and also government structures, have encouraged the formation and running of PLHIV Support groups and Income Generating Projects (IGPs) such as keeping of poultry, goat rearing and nutritional gardening. It is in these groups that our target population is found.

Most people in this region have a four-year secondary education and they might have failed their exit certificate, but their spoken and understanding of the English Language is good. At the District Hospital, there is a department known as Opportunistic Infectious Clinic (O.I.C) which deals with people living with HIV. This department meets with the registered HIV positive people for Gwanda South once every month for education on HIV issues and evaluation of some programmes undertaken by the members of Thusanang HIV and AIDS Project. As a member of the HIV educators' team, I noted with concern that there were many widows and widowers who are registered with this O.I.C department. It is within these parameters that the research took place. This study targeted surviving HIV positive spouses registered with Opportunistic Infectious Clinic (O.I.C) at the Manama Mission Hospital and also being members of the Thusanang Project.

Gwanda District has one of the country's highest HIV prevalence rates at 21.9% with 1267 new cases having been reported (ZNSA, 2016). At that level, the prevalence rate is way above the national one which is 15% and has some adverse effects on the lives of the people as Gwanda is a rural district with high unemployment rate. For their economical survival, people rely on subsistence farming which has always been affected by perennial droughts and this is one of the poorest district in the country. O'Brien and Broom (2014) observed that HIV was a significant

social, political and economic problem in Zimbabwe and that few researchers had explored people's experiences of living with HIV. The influence of traditional and religious interpretations of HIV created HIV-related stigma and discrimination especially in the rural Zimbabwe like Gwanda district. A positive HIV diagnosis has significant psycho-social consequences: it disrupts an individual's life trajectory and goals, including dramatic shifts in sense of Self, personal relationships, and participation in social activities (Macapagal, Ringer, Woller, & Lysaker, 2012). Macapagal et al. (2012) further argue that the narrative a person living with HIV tells themselves and others may indicate how well they are adjusting to their diagnosis and treatment.

### 4.5 Sample and Sampling Procedure

Purposive sampling represents a group of different non-probability sampling techniques. Purposive sampling relies on the judgment of the researcher. The main goal of purposive sampling is to focus on particular characteristics of a population that are of interest, which will best enable you to answer your research questions. The sample studied in this research was not representative of the population.

This study used homogeneous sampling and homogeneous means of the same kind. In this study, I looked at spouses who have lost their partners to HIV related illness and who themselves are living with HIV. Creswell and Plano-Clark (2011) define homogeneous sampling as a purposive sampling technique that aims to achieve a sample whose participants (people or cases) share the same (or very similar) characteristics or traits (surviving HIV positive spouses). A homogeneous sample is often chosen when the research question (what is the nature of the changes that take place in individuals' explanatory of their self in relation to their acquired HIV positive status, and in relation to the role that forgiveness may play through the dialogical self in the self-identity reconstruction process?) that is being addressed is specific to the characteristics of the particular group of interest (surviving HIV positive spouses), which is subsequently examined in detail. Creswell and Plano-Clark (2011) posit that homogeneous purposive sampling is virtually synonymous with qualitative research and specially fit for phenomenological research design. To say you will engage in purposive sampling signifies that you see sampling as a series of strategic choices about with whom, where and how to do your research. Two things are implicit in that statement; first is the way that your sample has to be tied to objectives and second is an

implication that follows from the first, that is, there is no one best sampling strategy because which is best will depend on the context in which you are working and the nature of your research objectives.

The target population was the surviving HIV positive spouses in Gwanda South Constituency. The sample was selected at Manama District Mission Hospital at the Opportunistic Infectious Clinic (O.I.C), where the HIV positive people collect their monthly drug-allocation. People living with HIV gather once every month voluntarily to receive lectures on HIV, psychological well-being, stress management, small business management, and a lot more about life in general. The following criteria were used to determine suitability for participation in the study: widows or widowers between the ages of 21 and 50; HIV positive widow or widower; should have been a widow or widower for a year or more; found their HIV status after marriage; able to endure interviews lasting up to an hour; people who met the above criteria were invited to volunteer to be the research participants. The sample size was 5 widows and 5 widowers. Ages of 21 to 50 were chosen because people in this age range are considered as highly risk in heterosexual transmission of HIV in marriage institutions. While the legal age of majority in Zimbabwe is 18 years, the threshold of adulthood is still recognised at 21 years old.

In Zimbabwe, grieving a lost spouse is a process that includes traditional funeral rites, rituals, ceremonies to ensure spiritual health and community support, all these should take a minimum of one calendar year. It was with this in mind that I chose to work with surviving HIV positive spouses who had been a widow or widower for a year or more so that I would not interfere with their grieving and mourning period. I decided to work with the participants who discovered their HIV positive status after marriage because the study assumption was that the couple got married when they were both HIV negative or they did not know their HIV statuses and assumed that they were negative.

### 4.6 Research Instruments

The most common interview used in phenomenological research, and indeed in all qualitative research, is the semi-structured interview. This approach to interviewing has a long history in psychology and represents a trade-off between consistency and flexibility that best meets the needs of many qualitative researchers. Consistency is maintained through the use of an interview schedule consisting of a series of questions and prompts designed to elicit the maximum possible

information (see Interview Schedule Guide). As can be seen from the interview-schedule, the questions tap different aspects of experience being explored. They should not be treated too rigidly, however. It is important in semi-structured interviewing that the interviewer works with his or her questions in the light of the conversation that occurs with the interviewee. If questions are answered earlier, then the interviewer needs to work with this and not attempt to enforce the schedule rigidly. There may also be topics that emerge that had not occurred to the researcher during the production of the interview schedule, and these should be followed up if it is thought that they will shed light on the topic. The aim is always the development of rapport to enable joint exploration of the participant's world view concerning the topic; the schedule is merely a guide to enable the researcher to do this as effectively as possible given the constraints of time and money that the researcher (and the participants) inevitably faces. All the interviews were recorded on audiotape.

Individual interviews were divided into 3 parts per participant and each participant was interviewed continuously to cover the 3 parts. Each interview lasted at most one hour and this was done to cut off the inconveniences for calling the participants back. However, the participants were free to stop if they felt that they were tired or that they could not continue. Participants, who stayed far from the Hospital, were given a choice to come to the Hospital or to be interviewed at their homes. Those that chose to come to the Hospital were given transport fare, breakfast and lunch per interview. In the first part of the interview, I tried to establish the context of the participant's experience before marriage. That was referred to as "Life before marriage." The second part of the interview was in two sections: Section One looked at marriage before discovery of HIV status; Section Two looked at marriage life with HIV positive status up to the death of the spouse. The third and final part of interview also had two sections. Section one looked at life after the death of the spouse. Section Two looked at the future life. In using the structure of the three-parts-interview method, with each part having its own distinct purpose, it was hoped that the context, the detail and the meanings were to emerge in the interviews.

### 4.7 Data collection procedures

Phenomenological research is often conducted with marginalised populations (surviving HIV positive spouses), mostly because these populations tend to be in the periphery and margins of society and their experiences and views are hardly sought, therefore, phenomenological research

can be more appropriate for describing their lives (Sieber, 1993). As phenomenological researchers, it is important, therefore, to consider ethical issues when doing this type of research since people are entrusting us with their own personal life experiences, which at times might be very sensitive (for example discussing one's HIV status).

I applied for clearance to embark on this research from the Ministry of Health and Child Welfare in Zimbabwe. After the approval of my research proposal by the University of South Africa (UNISA), I sent the proposal with the ethical clearance application to carry out the research to the Ministry. I had informally talked to the authorities at the Opportunistic Infectious Clinic (O.I.C) about my research. With the letter from the Ministry, I then officially approached the Clinic. As an HIV educator among the target population, I requested from the Clinic to meet and address the target population. After having been given the permission by the Clinic, I organised the first meeting with the target population. At this meeting the purpose of the study was explained, expectations from the participants outlined, and time and date for the interviews set. On the issue of confidentiality, I explained to the participants that anonymity will be maintained, and I ensured this by providing all participants with pseudo names. All the materials used for interviews were kept locked in the office cabinet. A file containing information that identifies research participants, that is their names and their pseudo names, was created. Access to this information is limited to me and my supervisor. When I was satisfied that the participants had understood the requirements, I then gave them consent forms to read and sign. Participants were informed that they had a right to withdraw any time when they so wish. I requested for permission from the participants to record on audiotape all the interviews and explained that this was to ensure that I correctly captured their narratives. The interviewer's task was to make the participant tell the story of the area of interest in question as a consistent story of all relevant events from its beginning to its end. Riemann and Schutze (1987) assert that the narrative interview is begun using a generative narrative question, which refers to the topic of the study and is intended to stimulate the interviewee's main narrative. The latter is followed by the stage of narrative probing in which narrative fragments that were not exhaustively detailed before are completed. Hermans (1995) points out that the last stage of the interview is the balancing phase. Here the interviewee may be asked questions that aim at theoretical accounts of what happened and at balancing the story, reducing the meaning of the whole to its common denominator.

### 4.8 Data Analysis

Interpretive Phenomenological Analysis (IPA) (for example, Smith & Osborn, 2003; Smith, Flowers & Larkin, 2009) was the chosen analysis procedure for the current study. Smith (2008, p.67) argues that IPA is not a perspective methodology, but offers guidelines for analysis that can be adapted to a researcher's own personal style of working. Larkin et al. (2006) suggest that rather than a distinct method, it is more appropriate to understand IPA in epistemological terms as a stance or perspective from which to approach data analysis. In other words, IPA guidelines for analysis do not differ significantly from other forms of thematic analysis in their pragmatic approach to identifying themes in the data; instead, it is suggested that it is the dual emphasis on phenomenology and interpretation that makes the methodology distinct. Indeed, the use of IPA as a flexible method is reflected in the different approaches taken by the IPA studies in Brock and Wearden's (2006) review.

The choice of IPA was predicated on the following reasons: Firstly, IPA is consistent with the research aim, in that it is committed to the examination of how people make sense of their major life experiences (Smith et al., 2009). It is a phenomenological approach in that it is focused on exploring experience in its own terms. What it is like to be a widow or widower and at the same time being HIV positive? Secondly, IPA is both phenomenological and social constructionist, in that it is concerned with personal experience, but also involves interpretation, involving a consideration of context. The study looks at the nature of the relationship that exists between the surviving HIV positive spouses with their significant others.

Thirdly, IPA's idiographic nature is in keeping with the aim of this study. IPA is concerned with the particular, with revealing something about the experience of each of the individuals involved, and being able to say something in detail about the participant group (surviving HIV positive spouses). Smith et al. (2009: 29) describe how IPA's commitment to the particular operates at two levels. Firstly, there is a commitment to details, and depth of analysis and secondly commitment to understanding how particular experiential phenomenon has been understood from the perspective of particular people in a particular context. The aim of IPA is not to make premature generalisations about larger populations, but rather to arrive at more general claims cautiously, and only after the painstaking analysis of individual cases (Smith & Osborn, 2003). In keeping with IPA's idiographic commitment, each interview was first analysed in-depth

individually (Smith et al., 2009). Each recording was listened back to back at least once, and the transcript read several times. Initial annotations were made in one margin, with exploratory comments describing initial thoughts about the content, language, use and more conceptual, interrogative comments (Smith et al., 2009).

Each transcript was then re-read and the second margin used to note emergent themes drawing on both the transcript and the initial analyses. Each interview was analysed in this way until all ten interviews had been analysed to this level. The emergent themes were listed chronologically and then moved around to form clusters of related themes. Smith et al. (2009) detail how super-ordinate themes can be identified through abstraction (putting like with like and developing a new name for the cluster); subsumption (where an emergent theme itself becomes a super-ordinate theme as it draws other related themes towards it); polarisation (examining transcripts for oppositional relationships); contextualisation (identifying the contextual or narrative elements within an analysis); numeration (the frequency with which a theme is supported) and function (themes are examined for their function).

### 4.9 Transferability and Trustworthiness

Denzin and Lincoln (2002) point out that both subject and researcher are co-creators of the stories that are told. This creates subjectivism because there are no objective observations and there are only observations socially situated in the worlds of the observer and the observed. Qualitative researchers are concerned with trustworthiness. When the research goal is to provide a detail description of an individual's experience derived from personal narratives, the focus is not measurement but description and exploration. Description then becomes the cornerstone of the scientific method for qualitative researchers. Thus, the primary concern of the qualitative researcher is the question of whether the accounts and description generated from the interviews are valid and accurate portrayals of reality and obtained in a trustworthy manner. The purpose of the in-depth interview study is to "understand the experience, not predict or control that experience" (van Manen, 1990, p.22).

Seidman (2006, p.51) noted that "the job of an in-depth interviewer is to go to such depth in the interviews that surface considerations of representativeness and generalisability are replaced by compelling evocation of an individual's experience." However, this does not mean that results from a qualitative study cannot be generalised. In qualitative research, generalisability is known

as transferability (Guba & Lincoln, 1989). Richly described data or sufficient contextual information can provide researchers with enough information to judge the fittingness of applying the findings to other settings.

Fittingness was contingent upon producing thick descriptions of the data, based on the inclusion of the widest possible range of information. The three-interview-part-series allowed each participant to fully explain his/her experience and thus produced the desired description. In order to minimise the degree to which this phenomenological research is bound by its subjectivities, several procedures were used to improve the trustworthiness of the research findings. Trustworthiness implies strengthening the validity and credibility of analysis, rather than working towards ensuring reliability and validity as in traditional positivist research. Validity, in qualitative research, involves demonstrating that the interpretation (of data) is based on sound reasoning, systematically applied. Credibility infers that the research results are reasonable, possible and believable, not only to the researcher but to those researched. Positivist strategies assess for validity and reliability of the methodology and the instruments (Bastow et al., 2014).

Dependability in qualitative research strives to establish the ability of the research to be repeated over time in the same and different setting using the same instrumentation and methodological approaches as proposed by Bergold and Thomas (2012). Bastow et al. (2014), however, argue that the nature of truth in qualitative research is subjective even when the environmental conditions are the same. However, to address dependability in the research, I relied on the evidence gathered from the spouses surviving with HIV and I cross-questioned them for consistency.

### 4.10 Confirmability and Authenticity

Qualitative research tends to assume that each researcher brings a unique perspective to the study. Confirmability is the degree of neutrality in the research study's findings. In other words, this means that the findings are based on participants' responses and not any potential bias or personal motivations (Lincoln et al., 2011). This involves making sure that researcher bias does not skew the interpretation of what the research participants said to fit a certain narrative. Audio-taped interviews were used in this study to capture what the surviving HIV positive spouses said. To establish confirmability, qualitative researchers can provide an audit trail, which highlights every step of data analysis that was made in order to provide a rationale for the decisions made.

This helps establish that the research study's findings accurately portray participants' responses. Reflexivity is a technique that is useful in qualitative research, especially in phenomenological research and it is an attitude that a qualitative researcher adopts when collecting data and analysing data. The researcher has to look at his/her own background and position to see how these influence the research process. For this study reflexivity is presented on item 4.11 fully. The process of coding and identification of themes is argued to be closely linked with the quality of any qualitative research and therefore, it must be made explicitly (Tong et al., 2007). This, I, achieved by creating a table of themes inclusive of main themes, sub-themes and quotes from the participants where the themes were developed.

Schwandt, Lincoln and Guba (2007) argue that authenticity is an extension of the trustworthiness criteria because it enables questions to be asked about how interpretations are made and how this process has evolved. An important issue for qualitative research is that of authenticity. Adopting this approach means that participants become responsible for the cultural reproduction of the research inquiry in which they have a part and so have a stronger investment in ensuring that the outcomes of the inquiry are authentic. Authenticity is a crucial component of qualitative inquiry, and it remains elusive to qualitative researchers. To establish authenticity researchers engage in several processes to ensure that the findings are credible not only from the participants' experiences but also with regard to the larger implications of research. In this current research I empowered the participants by means of ethical clearance which ensured that informed consent and issues of confidentiality were clearly laid down for the participants before embarking on the research. The significance of the study was clearly spelt out for the research participants. I used a homogeneous purposive sampling procedure to get information rich participants (surviving HIV positive spouses) so as to have wide representation of people who have relevant relationship with the phenomenon.

### 4.11 Reflexivity

Reflexivity is the process of reflecting on yourself as the researcher, to provide more effective and impartial analysis. It involves examining and consciously acknowledging the assumptions and preconceptions you bring into the research and that therefore shape the outcome. The motivation to research on the forgiveness through the dialogical self theory on qualitative track

of self-identity reconstruction among surviving HIV positive spouses arose from professional and personal encounters with HIV and AIDS.

At a professional level, my journey on HIV and AIDS issues started in 2002 when I was appointed the HIV/AIDS Club patron at a school where I was teaching in Gwanda district. I attended many workshops on HIV/AIDS issues on behalf of the school and my club. I became the focal person at the school on all issues pertaining to HIV/AIDS. In 2005 I completed a certificate in HIV/AIDS education with UNISA and subsequently the school seconded me to the District Action AIDS Committee (DAAC). At DAAC, I was then appointed to be in charge of Information, Education and Communication (IEC) about HIV. It was at DAAC where I travelled across the Gwanda district working with organisations and projects involved in HIV/AIDS where I became the HIV educator and facilitator of HIV/AIDS programmes.

My knowledge and experience in HIV/AIDS took me to Midlands State University (MSU) where I was in charge of HIV/AIDS modules in the Department of Psychology. After training as a research and community psychologist I taught HIV/AIDS and the Community modules at masters' level in the Department of Psychology. With my students we did researches, presented papers and held workshops with organisations in involved with HIV/AIDS such as Thusanang HIV and AIDS Project based at Manama Mission Hospital in Gwanda South Constituency in Matabeleland South Province. It was through our outreach programmes that I found out those communities had attitudes towards people living with HIV. My interest in the research on HIV/AIDS deepened when I realised that there was HIV related stigma, shame, denial and discrimination. As a research and community psychologist I then opened what I termed "Attention Clinics" where I would meet people living HIV one on one as individuals after workshops, it was for those who wanted to discuss issues related to HIV/AIDS. To my surprise many people had a lot to say and the booking for "Attention Clinics" were always fully booked. Most of the people living with HIV who attended the "Attention Clinics" wereeither widows or widowers and this laid the foundation to my research.

At a personal level, I wish to acknowledge myself as part of the setting and not detached from this research study. In phenomenology, researchers are encouraged to suspend their biases and assumptions about the phenomena. Mkabela (2005) contends that it is only when we suspend the natural attitude that we begin to see the constitution of the conscious experiences of phenomena.

However, Gilbert and Sliep (2009) suggest that the aim of suspending biases and assumptions should be reflexivity and not to attain objectivity.

I grew up in a rural village of Gwanda South Constituency, growing up in a family and village with deep cultural roots. I was also made to experience how the dead are treated and learnt the burial rites. I learnt that some illnesses are caused by witchcraft and others are caused by natural forces like germs. My first encounter with HIV was in 2004 when my sister's husband, who at that time working in Bulawayo was found to be HIV positive and later died. Around the same time my second sister tested HIV positive and also later died from HIV related illness. My surviving sister and my brother-in-law were diagnosed HIV positive. These close encounters with HIV were shocking for me. My sister and my brother-in-law were shattered by both the death of their partners and being diagnosed HIV positive. They were the first widow and widower in my family to be surviving HIV positive spouses. They never recovered from their loss and eventually passed on from HIV related illnesses within a year apart after surviving for almost 5 years with HIV.

Gwanda South Constituency is a rural community and the cultural precepts of this rural community were acknowledged and followed in keeping with and accepting the value of understanding an orientation to collective values in rural indigenous culture. Mkabela (2005) describes this as using the collective as a centred paradigm. This paradigm recommends that researchers adopt a participatory approach which allows for learning by, with and from community members in order to establish a working relationship in which people's interests and values are more authentically represented in research. This served me well as a known person in this community. Moreover, spaces of social action created by activating relationships with others provide possibilities for the development of transformational agendas that foster new social practices and institutions (Gilbert & Sliep, 2009). This attitude was advanced by complying with certain expectations from community members. The tacit implication in this collectivist setting was that a request for a help could not be refused.This made my relationship with theparticipants cordial and easy to relate during the interview sessions.

During the interviews I made an effort to overcome the effect of my subjective feelings and prejudgements on my questioning. I also guarded against these subjective feelings during the analysis and interpretation of the results. Reflexivity was particularly important for my study

because of the sensitivity of the topic I was researching. In addition, surviving HIV positive spouses, like other people living with HIV are a vulnerable group. I was reflexive in the procedures I used to recruit surviving HIV positive spouses. After explaining the inclusion criteria for participating in this research to the target population, I then invited for volunteers and I never pursued those who were not interested.

Two research participants who showed signs of using the interview sessions as an opportunity to vent out their unresolved psychological issues were referred to the hospital trained counsellors. I paid the two participants visit after two weeks to check on how they were doing. I found them doing very well but however, they expressed displeasure with people who come to their area to collect names of people living with HIV and orphans but never come back to support the people. They claimed that these people work on enriching themselves with resources meant for people living with HIV. They expressed their happiness for my visit to check on them.

### 4.12 Ethical Considerations

Participants were interviewed in private to avoid being labeled and stigmatised. The participants were told that during the interview session, if they developed some discomfort, the session would be stopped immediately and if the participant so wished, she/he could withdraw totally from the research without any negative consequences. That was also indicated in the informed consent form that the participant had signed. At the Hospital, there were trained counsellors that work with HIV positive people and they were ready to assist participants who would have developed any psychological discomfort during the interview sessions. However, during the interview sessions, no participant showed any sign of discomfort or opted out but there were two participants who used the interview sessions as an opportunity to vent out their psychological issues. These two were identified and referred to hospital trained counsellors for further conversations after the interviews. After two weeks of the interviews I went back to Manama Mission Hospital to check on how the two participants were coping and found out that they were doing very well and they were very happy with my visit to check on them.

Participation was voluntary and there were no monetary benefits for participating in this research. A number of measures were put in place to ensure non-maleficence and protect the autonomy of the participants. Thus, no harm was inflicted on participants directly or indirectly, intentionally or unintentionally as a result of the research. Interview transcripts and audio

recorders were kept at a secure location under lock and key by arrangement with the supervisor and the local adviser. The participants used fictitious names that are pseudo names to protect their identity and those were converted into codes in the final report. Interviews were conducted in private and there was no video recording to protect the identity of the participants. The disposal of audio recorders and transcripts were supervised by the supervisor and the local adviser upon the completion of the report and at a time determined by the supervisor.

### 4.13 Chapter Summary

The methodology was guided by the theoretical framework for conducting qualitative research within a dialogical self-constructivist paradigm. The interpretive qualitative paradigm was used with phenomenological research design to conduct this research study. A homogeneous purposive sampling technique was used to select ten participants. In-depth semi-structured interview guide was used to solicit for information from the participants. Interpretive Phenomenological Analysis (IPA) was used as an analysis procedure. Data collection procedures took into consideration the ethical issues for human participants and the dissemination of findings.

# CHAPTER FIVE

# RESULTS

## 5.1 Introduction

Interpretive Phenomenological Analysis (IPA) of the ten semi-structured interviews resulted in the emergence of master and subordinate themes. The exploration of these master themes and their constituent superordinate themes (see Table 5.2) form the basis of this chapter, with each theme illustrated by verbatim extracts from the interviews. Interpretive Phenomenological Analysis (IPA) was carried out both thematically and ideographically through the presentation of each participant. I began this chapter by presenting a summary account of each of the ten participants' lived experience of self-identity reconstruction. Introducing the participants in this way was important, since entering the text and meeting the participant as whole is fundamental to the process of the hermeneutic circle. It demonstrates the uniqueness of each participant; the meanings they make of their HIV-positive status and the meaning I made out of their meaning-making. Following this, I described the main themes that emerged from the analysis of the transcripts. I then explored each theme and related subthemes in greater detail providing verbatim extracts to illustrate and support the findings. The research tracked how individuals understand themselves after a life-changing event has occurred.

## 5.2 Participants

The demographic information of the participants is illustrated in Table 5.1 below.

Table 5.1 Demographic information

| Participant Pseudonym | Sex | Age in years | Educational level | Number of children | Years after the death of spouse |
|---|---|---|---|---|---|
| Percy | Female | 43 | "O" level | Nil | 4 |
| Sharon | Female | 40 | "A" level | 1 | 6 |
| Matunzeni | Female | 50 | Grade 7 | 2 | 5 |

| | | | | | |
|---|---|---|---|---|---|
| Matika | Female | 47 | “A” level | 2 | 1 |
| Thando | Female | 38 | Degree | 2 | 2 |
| Mafana | Male | 50 | Diploma | 4 | 4 |
| Derek | Male | 45 | Degree | 2 | 2 |
| Nhlanhla | Male | 38 | “O” level | 2 | 3 |
| Mncedisi | Male | 49 | Grade 7 | 5 | 2 |
| Methembe | Male | 46 | Form 2 | Nil | 2 |

As indicated in the previously, the participants were given pseudonyms for protection of their identities. While the interviews showed a lot of similarities within the self-identity reconstruction experience among the surviving HIV-positive spouses, each individual came with their own unique experiences of the process. The descriptions of each participant aim to give a summary of their phenomenological experience of living with HIV including their self-identity reconstruction of a new self. Throughout, the participants would be referred to with their pseudo names given on the Table 5.1 for the protection of their true identities and to ensure confidentiality.

### 5.2.1 Percy

Percy is a 43 year-old widow born in an extended family and is a Christian. She knew very little about HIV and valued marriage and hoped for a happy marriage. She was a reserved person from a highly supportive family. She got married at the age of 26 years through a white wedding and the husband was a teacher who stayed with parents. She lost her only child at birth. Her husband was always complaining of some ailments. There was no protection in their sexual life because they trusted each other.

The husband was tested first as he was always sick and then she also tested and both were found to be HIV positive. She was devastated by her results while her husband quickly accepted the results. It was difficult to inform their significant others as they were respected people in the community and in the church. Upon disclosure they suffered stigma and discrimination and the

husband was ill for 6 years. She had difficulties in taking care of him, but family members were of great help. Her husband eventually died and it was difficult for her to accept that her husband had brought HIV home and she regretted not staying with him at his work place as she believed it is there that he contracted HIV.

While her husband's death was painful, she felt relieved of nursing him. At the time of the research, she was getting support from the church and siblings. However, she was finding it difficult to forgive her husband. Her relatives thought of her as a dying person and the church and community still stigmatised and discriminated against her. She got her strength from praying to God and sustained herself through being a vendor.

Percy did not entertain any thought of re-marrying because of her mature age. She is trying to live a positive life and to adhere to her treatment. She works hard in her garden and sells the produce she harvests to the local villagers. She does not involve herself too much in the issues of HIV and AIDS because she fears to be stigmatised and discriminated against by the society. Her understanding of HIV and AIDS has improved and her major regret is not having paid attention to education when there was still time.

### 5.2.2 Sharon

Sharon is a 40-year-old widow born in a small family, a Christian and an "A" Level certificate holder who valued no-sex-before-marriage and dated few boys from the same church. She had limited knowledge on HIV and AIDS and she expected to get married and live happily thereafter. She got married at the age of 27 years through a white wedding and had two children of which one died at the age of two years due to HIV related complications. The family was generally healthy, only the husband started to be sick shortly after the death of their child. They lived happily, trusted each other and never used condoms in their sexual life and she thought HIV was for the prostitutes.

Sharon was shocked to learn about her HIV positive status when she tested during her pregnancy and it took her a while to disclose to her husband. There was a lot of blame games but eventually her husband was suspected to have brought HIV home. There was support from relatives although stigma and discrimination persisted and her husband was ill for some time and

eventually died. She felt relieved at the death of her husband and she regretted marrying him. This is making it very difficult for her to forgive him even after his death.

Sharon is not feeling guilty but angry at her husband for bringing HIV to her life. While stigma and discrimination are still a problem, she was at peace with her relatives, and her 18-year-old daughter is the reason she was going strong. At the time of the study, Sharon had accepted what had happened to her life. She had no plans of remarrying as she was happy living only with her daughter. Taking her medication is number one thing in her life. She did not want to get involved in HIV and AIDS related organisations because she wanted time to herself to raise money for furthering her studies. She did not want to discuss HIV and AIDS issues with her daughter because it is hard for her and she hopes these issues are being covered at schools. Her understanding and fears of HIV and AIDS had improved and she felt that she can now relate well with the idea of being HIV positive.

### 5.2.3 Matunzeni

Matunzeni is a 50-year-old widow who went as far as Grade 7 and grew up in a broken family in a rural area staying with relatives and did not go to church. She saw marriage and sex as means of having children and she had several boy-friends and had sex with all of them. She was not sure of herself, her knowledge of HIV and AIDS was limited and she never had a good upbringing. She got married customarily at the age of 20. She remained at her husband's rural home while he worked in the Mines and she had two sons aged 30 and 26 years, respectively. They used to live a happy family life and never used any form of protection in their sexual life. She used to think that HIV and AIDS were for the prostitutes.

Her husband was always sick at work and he was taken to the hospital where he was tested and found to be HIV positive. She also went for testing and found that she was HIV positive as well. She was so worried to the point of wanting to commit suicide and their sexual life was heavily affected as she refused to be intimate with him although he insisted on the use of condoms. It took them some time to disclose to their significant others. Their relatives were very angry and her in-laws blamed her for infecting their son with HIV. Her husband died 5 years ago and she remembers him as a hard worker. She is still angry with a lot of unanswered questions. She believed that her husband got HIV from the mines. She felt that she had moved on and forgiven her husband although it is difficult. She felt stigma and discrimination make it difficult to live a

happy life when one is HIV positive. She had now turned to God for strength. She says it is painful to live with HIV and her life had changed so much. She is surviving through vending and rearing chickens. It pains her to talk about HIV and AIDS to her two sons however; whenever she did talk to them it would be out of anger. Her understanding of HIV and AIDS has improved greatly.

### 5.2.4 Matika

Matika is a 47 year-old widow, born in an urban area, educated up to "A" level and coming from a small intact family and a Roman Catholic Christian. She was taught that marriage was about love, trust and respect, she started her sexual life at Form 2, very young, had sex several times with many different boy-friends and enjoyed clubbing a lot. Her knowledge of HIV and AIDS was very good. She got married at the age of 33 years through a white wedding. Her husband owned a house and they have 2 children aged 12 and 10 years, respectively. Her husband was always ill from different ailments but their marriage was full of love and they trusted each other to the level of not using protection during sexual intimacy. They rarely discussed issues of HIV and AIDS at home and there was no history of HIV testing beside when she was pregnant.

She was tested during pregnancy and found to be HIV positive. Her husband also got tested thereafter and tested HIV positive, and was devastated by the HIV positive status and suffered heavily from stress and depression. He became seriously ill and due to advanced illness, they informed their significant others about their HIV positive statuses. Her in-laws were very hurt blaming her for infecting their son with HIV. Her husband was ill for some time and the help was forth coming from relatives, church and neighbours. Her husband died a year ago and she still had fond memories of him. She blames herself for the death of her husband. She remembers her husband always and her wish is that her husband would forgive her. She still visited her in-laws although they hate her and stigma and discrimination are still a major problem in her life. She draws her strength from her children. She regrets her past life when she used to sleep with men without protection.

Matika believes that she is too old for re-marrying and she had not yet moved on as far as healing is concerned, but she hopes with time she might. She is managing to cope with medication although it is difficult. She is heavily involved in the HIV and AIDS organisations.

She discusses HIV and AIDS issues with her children a lot because she does not want them to make similar mistakes she made. She now has a better understanding of HIV and AIDS.

### 5.2.5 Thando

Thando is a 38 year-old widow with a university degree. She attended urban schools, came from a big family with no religious background. She viewed marriage as an integral part of human life. Thando had many boy-friends at an early age and she knew about HIV and AIDS. She got married at the age of 23 years through customary marriage. She and her husband stayed with parents for a while before moving on to their own home. She has two children aged 10 years and 6 years, respectively. Her husband worked in South Africa and came home once after a long time. This resulted in her having extra marital affairs with some men in the neighbourhood. She never protected herself against diseases during sexual intimacy both with her husband and boy-friends. She never thought of HIV and AIDS at all.

She was the first to know her HIV status. She was suffering from many ailments when her husband was away in South Africa and she decided to go for testing due to persistence of her illness. It took her a long time to disclose to her husband and only disclosed when her husband was seriously ill. She advised her husband to go for an HIV testing and after testing he found out that he was HIV positive. They never really disclosed but family members came to know when her husband was no longer going back to South Africa for work. She got some support from family members and the nearby clinic. They consistently accused each other as to who could have brought HIV home and she always regretted for them not staying together in South Africa.

The death of her husband pained her and she accuses herself, she feels very guilty and blames herself for what she did when her husband was working in South Africa. She got support from her relatives but her in-laws blame her for the death of their son. She was failing to forgive herself. For Thando, life was tough and it has been worsened by stigma and discrimination. She wished that married people should be faithful and test for HIV more often. She did not consider remarrying at all and hoping to move on as she takes her medication without fail. She wanted to continue with her studies and eventually become a businesswoman. She does not discuss any HIV and AIDS issues with her children because they are still too young to understand. Her understanding of HIV and AIDS is now better and she will always forever regret not having gone to South Africa to stay with her husband.

### 5.2.6 Mafana

Mafana is a 50 year-old widower who was educated up to tertiary level. He came from an extended family with a great Christian background. He viewed marriage as an important stage in human life and believed in no-sex-before-marriage. He dated few girls from his church, but never had sex with them and his knowledge of HIV and AIDS was very limited. .He got married at the age of 28 through a white wedding. He owned his own house where he lived with his 4 children and they were a healthy family that valued the church and God. With his wife, they trusted and respected each other; hence, there was no need for protection during sexual activities. They saw no need to discuss HIV and AIDS issues as they both came from a strong Christian background. There was no need for HIV testing as to them HIV was for the unholy.

Mafana suffered from Sexual Transmitted Infections (STIs) after sleeping with a lot of women from his church. He tried to seek medication from private hospitals, it was difficult and taking long to heal, so he ended up going for HIV testing and was found to be HIV positive. He never disclosed to his wife about his status, however, his wife through mandatory testing at pregnancy, she was found to be HIV positive. She came home and disclosed to him about her new status and they both went for testing and they were confirmed HIV positive. His wife was so disappointed to the extent of falling sick and as a result of stress and depression, her condition worsened. Family members and relatives came to know about her illness and HIV status. She endured stigma and discrimination as people looked at her as the person who brought HIV home. It was difficult to care for her as he knew the truth of who brought the HIV home but could not confess. He was pained, guilty and angry, and he cannot forgive himself over the death of his wife. He tried to commit suicide but failed to, because he thought of his children. He continues to pray for forgiveness.

It was difficult at first for Mafana, but now he is used to living with HIV. He has learnt that in marriage faithfulness, frequent tests for HIV and condom use are very important in the prevention of HIV transmission. He is not entertaining any idea of remarrying because he wanted to look after his children. He had not forgiven himself and thinks of his wife daily. His children help him to take his medication. He was heavily involved in church organisations of HIV and AIDS related issues. He discusses a lot of HIV and AIDS issues with his children and he has

improved a lot in terms of understanding HIV and AIDS. His wish is for his wife to forgive him for what he did.

### 5.2.7 Derek

Derek is a 45 year-old-widower with a university degree. He attended rural schools and later urban schools. He came from an extended family with a Christian background which valued marriage life a lot. He was exposed to clubbing and he was sexually active as he was growing up and dated a lot of girls. His knowledge of HIV and AIDS was very good, but unfortunately he feared impregnating girls more than acquiring HIV. He got married at the age of 30 years through a white wedding and had his own house. He had two children of 9 and 5 years old. He never had protected sex at home because he trusted his wife and they were in a stable marriage.

He was a regular blood donor and it was through donating blood that he discovered his HIV status. He got disappointed, but quickly realised where it all came from. He told his aunts who in turn told his wife. She was devastated. She then decided to go for testing and she was found to be HIV positive. She was so stressed and depressed by her new status and fell ill. Her health quickly deteriorated. It became worse when she was visibly sick; she got affected by stigma and discrimination. He was pained by the death of his wife. He was afraid to live without his wife and looking after his children without their mother. He regretted his university life where clubbing was a daily life.

He still thinks of their wedding day and the love she had, he is pained to think that he infected her with HIV. He is angry at himself and feels very guilty of his past deeds. Stigma and discrimination are a major problem than HIV itself. He explained how difficult it is to live with HIV as one needs to eat healthy, take medication and deal with stigma related issues. He has learnt a lot about HIV and AIDS from his wife's illness and death. He thinks of remarrying because he is young and his children were also young and need a mother figure at home. He promises to tell his new partner about his positive status right at the beginning. He is heavily involved in HIV and AIDS organisations as a way to pay back for what he did to his wife. He works hard to invest so as to further his education. He does not discuss HIV and AIDS issues with his children because they are still too young to understand.

### 5.2.8 Nhlanhla

Nhlanhla is a 38 year-old widower from an extended family with a strong Christian background. He was educated up to Form 4 at rural schools, enjoyed playing soccer and loved clubbing. He valued marriage, wished to get married, own his home and have his children. As he was growing up he used to date many girls and would be intimate with them in the bush. He used to hear about HIV and AIDS and thought it was a disease for the urban people. He got married at the age of 24 years through customary marriage. He stayed with parents before building his own house with his two young children. He lived a healthy life without illnesses at home before moving to South Africa. They never used protection in their sexual life even though there were rumours about local teachers having love-affairs with his wife. He never discussed any issues related to HIV and AIDS; even testing for HIV was never an issue at home although he was also involved in extra-marital affairs in South Africa.

His wife was tested for HIV and was found to be HIV positive when she fell seriously ill. She never disclosed to anyone about her HIV positive status. He only discovered by mistake that his wife was taking ARV drugs. When he left home there was a fight and as a result many people in the village came to know that his wife was HIV positive. His parents got angry over the issue of him going to South Africa; he was heavily affected because he left for South Africa and never returned for a long time while his wife was ill. His parents, neighbours and relatives took care of his wife. He was sending limited funds through his parents because he was angry with his wife. His wife died when he was in South Africa and he did not come for her funeral and burial. However, later he also fell terribly sick that he could not work and was forced by illness to come back home. He regretted not having forgiven his wife and failing to attend her funeral. He wishes he could have taken his wife to South Africa.

Nhlanhla blames himself for leaving his wife behind when he went to South Africa when his wife needed him most. He has learnt a lot from being HIV positive, he derives strength from his children and is now working hard for their lives. Nhlanhla finds it hard to live with HIV and as a result perceives his future to be bleak. He has learnt the importance of being faithful and trustworthy to one's partner. He considers remarrying for the sake of his young children, but also thinks people might not be willing for they know his HIV status. He thinks that he has not

forgiven himself and his wife. He is not involved in any HIV organisations because his knowledge of HIV is limited and fears stigma and discrimination.

### 5.2.9 Mncedisi

Mncedisi is a 49 year-old widower with an African traditional religious background. He went as far as Grade 7 in education and comes from an extended family that values polygamy highly. He grew up dating many girls and engaging in sexual intimacies with all of them. HIV and AIDS were seen as issues for urban people. He was inspired by his grandfather who had many wives, thus the reason he also had two wives and he was known as a charmer boy in his early years in life. He got married to his first wife at the age of 24 through customary marriage, he then got married to his second wife at the age of 30 years; the reason he decided to marry a second wife was that he wanted a boy child which the first wife could not give him. By the time of research, he had 5 children, 3 girls from the first wife and 2 boys from the second wife. His family was healthy without any history of illness and his wives lived happily together. Issues of protection during sexual activities were a taboo and condoms were viewed as Western impositions, thus they never introduced condoms in their sex life. HIV and AIDS were also viewed as urban diseases and never to be discussed by well-behaved rural people.

Mncedisi's first wife got bed-ridden, due to HIV, they tried all traditional methods but all failed to help her get better, that is when they opted for urban hospitals. She got tested for HIV and she tested positive. Mncedisi was also tested for HIV and he also tested positive, the second wife also was tested for HIV and she tested positive. There was some fight over the issue of testing HIV positive in this family which made it to be the talk of the hospital and the village at home. His wives started accusing each other and his sexual life changed totally with both of them and the first wife became seriously ill due to stress and depression. The second wife refused to take care of the first wife because she felt that she was being accused of having brought HIV home. Life became tough and difficult at home, however, the relatives assisted in caring for the ill. Eventually the first wife died which led to some quarrels at home.

Mncedisi's views about the world changed when he realised that he was HIV positive, he says he became a new person and his views about the world were altered. Remarrying was, however, out of his mind and he is working hard to re-unite with his second wife, he has not moved on at all. He is adhering to Anti Retroviral Treatment (ART) and also participates in HIV related

programmes and workshops carried out in his village. His future is only based on his children whom he wishes to take care of as they grow without their mother. His knowledge on HIV is limited, hence, he could not teach or discuss with his children, but through attending training and workshops, he hopes to learn more about HIV.

### 5.2.10 Methembe

Methembe is a 46 year-old widower with an African traditional religious background from an extended family that is highly supportive of each other. His education did not go beyond junior certificate, he was educated up to Form 2 at rural schools, and his knowledge of HIV and AIDS was limited. He believed that a man should marry, build a home and have children, thus Methembe wished to have a large family. Before and after marriage, Methembe had many girl-friends; and would have unprotected sex with most of them. He got married at the age of 22 years through a customary marriage. He managed to build his own home close to that of his parents where he lived with his wife. He had one child who died of HIV related illness at the age of 5.

When Methembe's child was seriously ill, the child was screened for HIV and tested positive, thereafter, both parents were subsequently tested for HIV and both tested positive. It was hard for both parents as they tried to figure out who had brought HIV home. They agreed to use protection for any sexual intimacy as recommended by the health practitioners so as not to cause re-infection or create a drug resistant HIV strain. Methembe and his wife agreed not to disclose to others about their HIV status, however, they eventually disclosed to significant others when the child died. His wife's illness took its toll and it was difficult to nurse and care for her, eventually leading to her death. He, however, got support from relatives and friends. On her death bed, Methembe's wife disclosed that the child did not belong to Methembe, after a long time in marriage without a child, the wife had thought of having an extra-marital relationship so as to save her marriage, and, it was suspected that this was how she contracted HIV. Methembe blamed himself for failing to give his wife children, and said, if he had been able to give her children, she would not have had an extra-marital affair and maybe she would have been alive to date.

To Methembe, it is painful to live with HIV and he is always thinking about death. Seeing graves of his child and wife reminds him of the reality of death. He has learnt the importance of

communication, his wife could be alive if they had discussed and shared their problems of not having a child. He is not thinking of remarrying because of his impotence, he had not moved on at all. He saw no use to participate in HIV and AIDS programmes because he believed he would not get any help that benefited him personally. At the time of the research, he believed he had no future and his knowledge of HIV and AIDS is still limited. He regrets his impotence and wishes they could have talked about it with his wife.

### 5.3 Emerging Themes

Interpretive Phenomenological Analysis (IPA) of the ten semi-structured interviews resulted in the emergence of four master themes. These were as follows:

#### 5.3.1 Self-identity track

#### 5.3.2 Relationship with significant others

#### 5.3.3 View of past self and future self

#### 5.3.4 Forgiveness as a way of moving on

It should be noted that I presented these themes as one possible account of the experience of participants' self-identity with HIV. They did not cover all aspects of their experiences of self-identity with HIV and I selected them due to their relevance to the research questions. I acknowledge that they are a subjective interpretation and that other researchers may focus on different aspects of the accounts.

**Table 5.2 Master Themes and related superordinate themes**

| **Master Themes** | **Superordinate Themes** |
|---|---|
| **5.3.1 Self-identity track** | **5.3.1.1 The idea of marriage and sex**<br><br>**5.3.1.2 Emotional journey in dealing with HIV related illness**<br><br>**5.3.1.3 Life without the spouse** |

| | |
|---|---|
| **5.3.2 Relationship with significant others** | **5.3.2.1 On being HIV positive and engaging significant others**<br>**5.3.2.2 Relationship with the significant others after the death of spouse** |
| **5.3.3 View of past self and future self** | **5.3.3.1 Relationship with the deceased partner**<br>**5.3.3.2 Remarriage**<br>**5.3.3.3 Relationship with children** |
| **5.3.4 Forgiveness as a way of moving on** | **5.3.4.1 Life choices in forgiveness**<br>**5.3.4.2 Turning to God**<br>**5.3.4.3 Acceptance and possibilities for a redefined future self** |

### 5.3.1 Self-identity track

Self as a mental representation of one's identity is revealed through the journey travelled by an individual from early life values. The self-identity track was traced through the subthemes identified within the master theme. HIV requires lifetime changes in physical health, psychological functioning, social relations, and adoption of disease specific regimens. Self-identity is affected by one's past behaviours and what significant others are saying about an individual (Petronio, 2012). The process of self-identity reconstruction involves understanding the embarked journey, and identifying the role one played at each and every stage of that journey. The responses of individuals to life eventualities will determine their self-identity reconstruction as they journey in life of changes and adaptation.

5.3.1.1The idea of marriage and sex

Participants found it difficult to live with the idea that they were HIV positive at the beginning of knowing their status, but gradually came to accept their status. Being shunned, gossiped about, stigmatised and discriminated against affected them a lot at the beginning. Some of the difficulties are articulated in the following excerpts:

Percy had this to say:

*At the beginning it was tough and difficult but now I am fine….. I have grown to accept what I have…..I live with my medication, it is a daily thing!! People are always looking at you with suspicion…… you do not trust anyone eish ….they laugh with you now and the next time you a subject of gossip so how do you trust them……..*

Mncedisi added this:

*It's a dark patch in life when you suffer from headache you think you will die the same day…. Any illness that attacks you, you always think eish that thing has started again……death occupies your life so much that sometimes you think like losing your head…..paranoia feelings of shame and embarrassment ……..you always want to explain to people who did not ask any questions……. I am just tired ….. This thing called HIV can eat you alive……..*

Matika says:

*It is hard to live with the condition. People point at you and they are always gossiping about you. At first it was very tough but now I have grown to understand it. I am only affected by the death of my husband. I eat well and keep myself happy with my children. I fear for my children when they are identified by my condition otherwise for me I have accepted this condition…….I still cry but I don't allow my status to stop me working towards my goals in life. I still worry about my responsibilities but I know that taking my medicine is the best thing I can do……..*

Sharon had this to say:

*I am a quiet and very reserved person. I was ashamed to be open about my condition due to fear of embarrassment and humiliation. Forgiving myself was the first step when my husband died but it was still the hardest decision for me to make. I am still very quiet about my status to my friends. But otherwise, I don't let my HIV status affect me in anyway. I am still normal……..*

Learning that one is HIV positive can be one of the most difficult experiences a person goes through in life. Embarrassment, humiliation, stigma and discrimination appear to affect the participants most as they try to figure out what it is to be HIV positive. But it is important to note that the participants were able to live happy and fulfilling lives. Ultimately, everyone's lives are different; how you cope with your diagnosis and how you move forward is dependent on how you dialogue within yourself.

Participants' backgrounds and individual and family values influenced some of the choices they made. The notion of one's values influencing how they approach life is critical in understanding the decisions they make. For example, beliefs about marriage (monogamy or polygamy), religions and other similar factors seem to have affected how the participants navigated and made choices related to intimacy and relationship in their lives. Some of these values are articulated in the excerpts below:

Mncedisi had this to say,

*…. Sex was just something small we could do it willy-nilly. Some of the girls we would take away their virginity but we wanted to marry virgin girls……you were also seen as a hero if you had a lot of girls and many boys will envy you especially if you came from a rich family…..the icing of everything was when you were discussing with others how much you were enjoying having sex with different girls…….*

Derek had this

*….. I dated a lot of girls and we engaged in sexual activities and boys who never slept with girls were seen as too backward…..boys who needed no respect from others….they would also feel ashamed of themselves and promise to indulge as well for them to be part of the group….*

Nhlanhla says,

*…. As I was growing up I used to take sex very lightly. We used to have sex in the bush with girls. We had girls and enjoyed sex ……. I used to date many girls and had sex with them…..it was just a game to all of us…… eish you look back and say these are things we use to do and wonder now but by then it was the norm for most of the boys….. we will boast about the number of girls we would have slept with…….*

The use of the word “we” from the male participants above seems to imply that there was a sense of wanting to please peers so as to show how much of a man one is. In addition, sexual intimacy appears to be linked to manhood where men feel the need to show their sexual prowess by being promiscuous. On contrary to this, a different narrative seems to apply to women, and this can be seen from the women participants’ reflections below:

Sharon quoted,

*……. As we grew up we were told that marriage was very important for any girl and my wish was to get married through a white-wedding…..I had to behave so as to be sure that I get the best man for my wedding……. What I wanted was to make sure that my parents would be happy at the end……mmmmh I never wanted to let down my parents……my parents were everything that I lived for…….so I tried to live a good life for my husband and always prayed to God to give me the best man as a husband……..*

Percy says,

*I am a Seventh Day Adventist and we were always told to get our husbands from the church….. I was raised to abstain from sex until marriage, for sex was the gift for the married and to me good life was about good marriage……if your marriage was bad then your life is also bad…. To me life was about marriage…..was always seeing future as a good wife……the preparation for any girl-child was based on becoming a good wife in future…….elders in church would address you as ‘This one will be a good makoti indeed’ and loved that and our parents will feel very happy to that……..*

The above statements show how most of the females went into marriage with hope and good intention for the future. In their early lives before marriage, they did not indulge in sexual activities as they regarded sex as sacred and was to be enjoyed only in marriage.

To participants, marriage represented commitment and the faithful love two people share. The findings highlight that for the participants marriage carries with it emotional intimacy, family, significant others, finances, communication, parenting, pregnancy, relationship, romance, sex and above all love.

Mafana had this to say:

*I got married at the age of 28 through a Christian white wedding! It was a great wedding indeed, everyone was very happy for us and the church was full of praises, we were made the role models in our small village. We were a healthy and happy family which was an envy of many… me and my small family we had our choir…..we sang almost every Sunday…….*

Thando says:

*I got married at the age of 23 in a traditional marriage known as customary marriage. All the traditional rites and rituals were performed according to customs and values to the satisfaction of our parents. We stayed for some time with our parents before we built our own homestead just next to parents' homestead. We were blessed with two bubbling kids and the family was a bubbling of love and happiness……..though we always missed my husband, the father of my children who was always absent as he worked in South Africa, paying us visit twice a year only due to work commitment……..*

From the research findings most of the participants married in their mid-twenties through either white wedding or customary marriage. All of their marriages had parental and community blessings, their marriages were further blessed with children and they lived happily as couples. The couples consisted of healthy people who were never sick and according to them, there was no need for HIV testing because everyone enjoyed life and couples trusted each other. HIV was considered as a disease for urban people as they always saw and heard of those who died as people from towns coming to the rural areas only for burial. The findings indicate that marriages were all healthy up to the discovery of their HIV positive status. The coming in of HIV positive status meant the change of life and redefining it anew as the participants had to learn how to live with being HIV positive.

5.3.1.2 Emotional journey in dealing with HIV related illness

When one realises that s/he is HIV positive, there is tendency of projecting the blame to the next person. Most participants blamed their late partner for bringing HIV home, they even expressed their anger and this is shown in the verbatim below. Marriages are characterised by such stark gender inequalities that marriage itself is a risk factor for HIV infection (Berman, 2015). The impact of married individuals learning of their HIV positive status is too heavy to the couples. Individuals actively respond to information about their HIV positive status, invoking protective

behaviour against future risk of HIV for themselves and their actual and potential sexual partners.

Matika had this to say:

*…..At first he was very angry mmmmmh ….he did not want to talk about it (HIV) with me, he thought I am the one who brought this disease at home, he couldn't face and stomach staying with me. My husband was extremely angry and it affected his health to the extent of becoming ill…….his anger culminated him falling sick and I think with a weakened immunity……..things just worsened……*

Matunzeni says:

*Mmmmmmh……. I lost trust in him, life became different and difficult, I stopped having sex even though he insisted on the use of condoms, I refused, I had a new life that was complicated to understand and felt very much embarrassed…..I always thought everyone was through what I was going through…….eish everyone is talking maybe we are the talk of the village….. HIV sure in my family it was difficult to imagine……..*

Nhlanhla says:

*I was very angry with my wife. I was working hard in South Africa when back home she was busy looking for HIV. I felt very much betrayed by her and was so angry that I just left for South Africa, I did not mind about what would happen to her and our children…….I just felt she deserved all what would happen to her……eish sorry I was very angry ……*

Mafana observes:

*Eish ……mmmmh … I was not really surprised when I found out I had HIV, after all I went to have an HIV test because I had all the symptoms you get soon after you are infected with HIV. The doctor who I saw before I had the blood taken for my test did not seem to think there was going to be much doubt about the outcome and told me to prepare for a positive result. Nevertheless, I was still a bit numbed by the result……..*

Anger appears to dominate the feelings to being diagnosed with HIV. Participants are upset about how they got the virus and angry that they did not know that they had the virus. Being

embarrassed is another issue that is coming out mostly from the participants indicating that stigma and discrimination is still an issue in HIV. Anger creates stress and depression among the surviving HIV positive spouses and as I believe that anger is an acid that can do more harm to the vessel in which it is stored than to anything on which it is poured.

Stigma and discrimination also makes people vulnerable to HIV. The participants reported being shunned by their families, peers and the wider community. Baltazar (2014) posits that stigma and discrimination limits the people living with HIV access to HIV testing, treatment and other HIV services. From the participants' views, HIV and AIDS are always associated with death, with disapproved behaviours and that HIV infection is the result of personal irresponsibility.

Derek had this to say:

*As educated people, we were respected in the community and many people looked up to us as role models. We enjoyed the esteem offered to us by the community and that made us different from others. However, all this dissolved as soon as people learnt of my wife's sickness and news travel quicker if you are an important person in the community. People started shying away and shunning us and many elderly people in the community were very much disappointed in us…mmmmh …eish… it was indeed….this thing is something in life….*

Percy had this:

*It was a double loss! I had lost my child, now it's my husband who is sick, and it's me who is also HIV positive…..what a loss……eish God ….why me…(*she sobs and I give her a piece of tissue*) …..People are talking……I have names given to me (*lowana otshisayo-*the one who is hot) ……some church members also shun me…….and some are too sympathetic to the extent of making me feel too hopeless ……. This thing (HIV) is just complicated and it complicates your life…….you wonder what next……you not sure because you like staying with death sentence at home waiting for the announcement and pronouncement of it……stigma and discrimination will hit you so much……*

The epidemic of fear, stigmatisation and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic. It complicates

decisions about testing, disclosure of status, and ability to negotiate prevention behaviours. An unwillingness to take an HIV test means that more people are diagnosed late, when the virus may have already progressed to AIDS (Walque & Kline, 2009). This makes treatment less effective, increasing the likelihood of transmitting HIV to others, and causing early death.

Home based care was perceived as an economically viable option available for People Living with HIV (PLHIV). The care comprised of emotional, adherence, nursing and financial support to PLHIV. Home based care was preferred over hospital base care as it ensured confidentiality and patient care without hampering routine work at home. Spouses avoided picking up any argument with their HIV positive partners. They never enquired about the source of infection and remained silent even if they were aware of their infidelity. As most of the participants were based in the rural area where the culture of collectivism is still practised, it was fairly easy to get support from family members, church members and community members.

Mafana says:

*It was difficult to see my wife in pain and worse for my situation, I knew that I was the one who brought this to her. However, other family members and my children made caring easier, the church members were always there to give us spiritual support……*

Methembe had this to say:

*Caring for my wife was a bit difficult…..you would remember that we lost our only one child to this thing (HIV)……now my wife was sick…. I was alone I felt my gods had abandon me….why me all this….thanks to my relatives who were always there for me……otherwise caring for this lady was going to something else I tell you…..you see as a man you need your wife and now that your wife is sick……..mmmmh eish what do you do…..mmmmh do you go out… (*laughs*…) no it's difficult for us men eish……..*

Caring for each other is based much on how you love each other. Most of the participants reported having a difficult time seeing their spouses in pain and wasting away drifting towards death. Participants shared how they felt after their partners were ill for a long time with little help they could offer, however, they appreciated the support they got from family during this hard time.

5.3.1.3 Life without the spouse

Losing a spouse can be devastating, whether the death is sudden or following a long illness (HIV –related illnesses). One day you are married; the next day you are single, alone, and grieving. Between the intense emotions, the lifestyle changes, and the many practical considerations that accompany the death of your spouse, you probably feel overwhelmed and anxious about your future. Over time, the grief will likely subside and you will construct a new self. When you grieve, you can feel both physical and emotional pain. There is a lot of finger pointing as to who is responsible for the other spouse's death (Berman, 2015). There is also survival guilt that affects the surviving spouse. Some of these issues are articulated in the excerpts below:

Mafana had this to say:

*Eish….. mmmh.....eish it was very painful indeed. It was indeed painful because I never told her the truth; I thought my life had ended with the death of my wife…… I tried to seek mercy from God. My wife died for something she did not know. I have failed my wife and children……I knew my wife was going to die but it was like I was not waiting for it……. When it eventually happened I was saddened……like she was never sick you see death…brings those memories….. It's like you didn't do your best to prevent this death……I am just guilty…..maybe if I had told her, she was going to understand……now she is gone and gone forever…….*

Matika added this:

*I blame myself…… I accused myself……I killed my husband; he was a good man full of love for his wife and children. I might not cry publicly but always cry for my husband. Down deep in my heart I know my husband loved us heartily and I really regretted why I took long to tell him about my status. If only I had told him earlier…….eish maybe things could have been different….*

The above shows that surviving spouses suffer a lot from survival guilt and search for answers for the death of their beloved spouses. The surviving spouses struggle with finding the new self as the death of their spouses also devastates the already devastated HIV positive surviving spouse.

After losing a partner to HIV, surviving spouses often engage in self-blame by ascribing to themselves the responsibility for the death of their spouses. Often such are cases when the

surviving spouse had engaged in infidelity which he or she suspects to have brought HIV into marriage and had, subsequently, led to the death of his or her spouse. The death of your spouse affects your head, heart and spirit. You are likely to experience a variety of emotions, feeling confused, disoriented, fearful, guilty, unloved, relieved, and angry all at the same time. The excerpts below capture some of these sentiments very well:

Percy had this to say:

*My husband died six years ago…..it's like yesterday to me eish….eish I think about him every day …..mmmmh he was the bread winner in this family, we used to get everything we wanted without any problem but now things have changed… life is tough we now have to fend for ourselves…. I sometimes miss my husband and cry.....cry…cry because we never had any chance to discuss this thing called HIV….. only if I had discussed with him maybe I could be in a better position to understand and accept that he is gone and gone forever…….I still have memories for my husband……..*

Mncedisi added:

*When I think of my wife I get lost in my thoughts ….eish you people you have not seen a good person if you didn't see my wife…….She was patient, loving, kind, sociable and a free person, she loved people naturally……Oh! My Lord save me our graveyard is here at home we see these graves daily! It had been tough to live without my wife; I have many unanswered questions…..*

Matunzeni had this to say:

*My world crumbed when I lost my husband to HIV related disease. The morning that my children and I discovered his body and realised that he had passed on, is one that was forever engrained in my memory. At first, it was a memory that brought pain, grief, and sadness. And while 5 years later, his death is still difficult to face, I have come to peace with his passing and have learnt to live life well……..*

The participants were feeling the pain of losing their loved ones because they are always fighting the feelings or the reality that their loved ones are gone. Pain comes from resisting the truth that they are HIV positive and that their spouses are no longer alive. Even after a long time has

passed after the spouse had died, the surviving partners said it was difficult to face the reality that their spouses were gone.

### 5.3.2 Relationship with the significant others

A successful and humane HIV cure requires not only the science of eradicating pathogens, but also the art of healing to restore harmony between mind and the body. Healing in the context of HIV cure is personal and interpersonal, biological and social, and will involve rebuilding connections between HIV patients and their social environment. Doka (2002) suggests that reconnecting HIV patients with their significant others is a necessary component of HIV cure, as this will help patients engage more fully in the HIV healing process. The significant others in an HIV positive person's life often need help themselves to come to terms with their own fears and prejudices, and the implications and consequences of their loved one's sickness and ultimate death. The relationship with significant others play a pivotal role in the life of a HIV positive person right from disclosure, their reaction to disclosure, the blame games on the sources of infection, the support system to the sharing and discussions on HIV issues.

#### 5.3.2.1 On being HIV positive and engaging significant others

Disclosure of HIV positive status to sexual partners or close relatives and friends (significant others) is an important act because it offers a number of benefits to the infected individual and to the general public. Sleap (2001) argues that disclosure to significant others would provide emotional and psychological support to HIV positive persons whereas disclosure to sexual partners could lead to the partners also understanding HIV counselling and testing services. Most of the participants' disclosure came from mandatory HIV testing for pregnant women and then men were also invited for testing while others it was due to ill health that they discovered their HIV status. On being HIV positive, participants had this to say:

Matika says:

*It was me who was tested first when I went for mandatory testing when I was pregnant, thereafter, I was asked to bring my husband, who also tested HIV positive.*

Matunzeni added:

*My husband tested first after he was urged to do so at his work place in the mine. In the mine they want a physically fit worker, my husband was always absent from work due to illnesses*

*which promoted the mine to ask him to undergo a thorough medical examination which included HIV testing.*

Nhlanhla worked in South Africa:

*My wife went for HIV testing on her own when I was in South Africa at work. She fell ill back home while I was at work place. She informed me about her illness and I sent her some money to the Hospital but she never told me anything about HIV instead she told me that she was recovering fairly. When she was admitted in the Hospital she tested positive to HIV and kept it a secret. It happened that when I came from work, one night she forgot to hide her HIV medication and when I saw it written ARVs, she lied to me and said the tablets were for the family planning. I was very suspicious; we quarrelled and fought until she told me the truth*

Disclosure creates the awareness of HIV risk to untested partners; it subsequently leads to greater uptake of HIV counselling and testing services. Disclosure to sexual partners enables couples to make informed reproductive health choices that may ultimately lower the number of unintended pregnancies among HIV positive couples, and even reduce the risk of HIV transmission from parent–to-child. In spite of all the benefits of disclosure, some people may decide to keep their positive HIV status a secret as we saw with Nhlanhla's wife. The disclosure of HIV positive status had potential risks such as blame, divorce, abandonment, physical and emotional abuse, stigma and discrimination, and being judged. As we saw Nhlanhla abandoning his wife and disappearing into South Africa after finding out that his wife was HIV positive.

Disclosing positive HIV status can be stressful. While a person may receive love and support from some of the people they tell, others may not be as accepting. The findings highlight that most of the participants had a Christian background and were respected members of their communities. As a result, news of their positive status evoked a number of mixed reactions from their significant others.

Methembe had this to say:

*My brother was shocked and quickly suspected my wife to be the one who brought HIV home but my in-laws put the blame on me. I know my wife was trying to look for a child to save her marriage because it was known that I was barren and I could not give her children. She had to*

*have extra marital affairs for the sake of the child but I know my wife loved me very much….This blame game could not work because I also loved my wife…. My wife loved me she had explained her story to me……..*

Sharon had this to say:

*It took me time to tell him. I was very upset. He knew that there was something wrong. He never said anything. He was not shocked to hear about our HIV positive status and we stopped anything to do with sex although he suggested the use of condoms, to me it was too late to think of protection. We had a torrid time and I knew he was the one who brought HIV home, I regretted marrying him. My family members were very angry and disappointed, they could not believe that I could be HIV positive eish mmmmmh it was embarrassing indeed……*

The above quotations show the difficulties of having to deal with family dynamics when someone is HIV positive. This speaks to the issues of stigma, disappointment and regret. HIV did not only affect the one who is infected as can be seen above, but significant others as well. Additionally, what the extracts above bring to the surface is other hidden challenges faced by families and difficult decisions that they have to make as a result of societal expectations, for example, the importance of having children at all costs, as highlighted in Methembe's story.

Kross et al. (2014) argue that there is a growing body of literature that examines the relationship between social support and HIV health processes and outcomes, particularly in such specific areas as medication adherence, clinical outcomes, and mental health outcomes. Engagement in HIV care refers to an overall holistic care of self to manage HIV disease, which includes access to, and active involvement and retention in both health care and general subsistence care. Social support is generally characterised as an enabling factor for engagement in HIV care. The relationship between the HIV positive individual and significant others are very important in the management of HIV; support during illness is very important for HIV healing.

Mafana had this to say:

*My children were always by my side during their mother's illness. They were quick to check whether their mother had taken her medication this made adherence easy. I appreciated the support I received from the church, church members would come home every week for prayers*

*and that went a long way in comforting us, though there were some sentiments of stigma among some choir members of the church……. My family members and members from my in-laws were of great help during this difficult time……People were always ready to assist indeed and wife's sisters came to stay with us so as to take full care of their sister….surely we thank God for the help and support that we got during the illness of my wife…..*

Methembe added this:

*You know my only son had died while he was young, this meant that we were only two of us at home, that is me and my wife……now there is my wife, she is sick and eish I am now alone madoda! Things were tough eish …. But thanks to my family, brothers and sisters who were always there for me, they made wife feel at home during her illness and my sorry situation better…..I could not have asked for more……*

Informal social support networks consist of family, friends and other community organisations such as churches. Caring for HIV positive ill person is highly taxing, it requires concerted effort from all angles of the society.

Aryle (2015) argues that human health is tied to a sense of connection to social environment, healing a patient means rebuilding the connection between the patient and his/her community which had been broken by illness. Support from significant others becomes key in the healing process. In the practice of HIV healing, social integration and social norms play an important role during the process of reconnecting HIV patients with their community.

5.3.2.2 Relationship with significant others after the death of spouse

The impact of death on the family system creates a structural void that requires homeostatic adjustments. The impact is also dependent on the cause of death such as natural death, suicide, HIV related illness or sudden death. Death can leave someone feeling very angry, abandoned and isolated. Some of the relationships that ensued are articulated in the excerpts below:

Derek describes his situation:

*I wondered what happened to her as if I didn't know that she was sick! I knew I would never see her again. She had been in the hospital. It was clear she was getting worse and her death was not a complete surprise. Yet, when she died, my feelings were of abandonment. It is not that I felt*

*my wife abandoned me. I just felt alone. I felt left alone. I am gradually getting over it by allowing other people into my space……*

Thando had this to say:

*I get support from my mother who visited me regularly. My in-laws are still angry with me. They are accusing me of infecting their son with HIV and causing his death. Whenever, the in-laws come it was for the children and they talk badly about me in front of my young children and I have even told my mother about it. My mother told me to be patient as it will come to pass but I am getting fed-up about this attitude of theirs……I am equally mourning my husband, they shouldn't treat me like my husband was nothing to me……I have children with this man….*

Percy added this:

*Remember I don't have a child. I am just alone here! I love my in-laws and the people around me but still I am alone, very alone among these people! What would you do yourself? I try to live with others but I am not like them. My husband died of HIV related disease and here I am HIV positive with no child of mine……I can't blame anyone it is life that God gave me….. I go church and pray…..mmmmmh church members do give support but I am still HIV positive and some members fear me …..eish….eish… (*sobs and I give her a tissue*) I was strong through my God for He had a reason for my life…… I am quite happy with the way I relate with people around me…… I can't complain……..*

The above narrations show that it is difficult to relate with significant others outside HIV positivity. The social environment is always reminding them that after all they are HIV positive. The contraction of HIV is easily viewed as being socially or morally wrong. The evident and persistent HIV related prejudice and stigma had been a barrier for community members to understand and accept HIV patients or involve them in daily social activities. The process of a person losing his/her sense of self is determined by daily interactions with the world outside of themselves. Stigma makes them feel shamed and guilty for their individual deviance from their social roles and potential violation and harm to the social relationship they cherish. Social norms toward HIV patients may also shake HIV patients' confidence in reconnecting with their community by encroaching their self-worth and self-identity.

Disclosure opens up your being to be questioned by your significant others on the issues pertaining to HIV. This means that when HIV positive individuals disclose their HIV positive status, they should be prepared to answer some of the uncomfortable questions from their relatives and also from their own children. For children, non-disclosure had been justified by parents based on the premise of protecting them from negative social and psychological consequences caused by disclosure.

Sharon had this to say:

*It is difficult for me to discuss HIV issues with my child! I think she is too young to understand and if she starts to ask me questions like where I got this HIV ……how do I answer this…..eish I don't want to create problems for me……I love her so much and I am very much afraid for her…… I hope they are taught these things at school……HIV has changed my life ….. I am not very comfortable discussing it worse off with my only daughter……it will mean I have to tell her that her father is responsible for my HIV positive status……you see I don't want to implant negative thoughts into my daughter's head about her father……maybe when she is old enough we will discuss……*

Mafana says:

*I discuss these things with all of my 4 children. I have seen and learnt a lot about issues of ignorance……. I have told my children that they are the reason why I am living and I want the best from them…….eish eish I am also guilty because I haven't said anything about the death of my wife, their mother, that I was involved……discussion is quite good for the children because now they understand that I am not well and I need to take my medication everyday so they assist me in terms of adherence. My children always remind me when I have a journey to pack my medication with me……. they also like to help me when doing some work and I tell you we work as a team in this home……I don't only discuss HIV with children but I am involved in the Church organisations that deal with HIV issues…… participate a lot in church activities……maybe I am doing all this for my late wife…….I want to die a good person……*

Tabana et al. (2013) argue that people living with HIV have different reasons for disclosure and non-disclosure. They hold dialogues within themselves for going public or not about their HIV positive status and they hold to their reasons dearly. Concealing HIV infection, being anxious of

unexpected breach, and living a double life may psychologically overwhelm HIV patients and undermine their self-esteem. The moral meanings and social stereotypes about infection modes are manifested among HIV patients themselves, which greatly impact their HIV healing process. The above excerpts show that disclosure brings with it a mixed bag of feelings as for Mafana, the disclosure is working very well with his children and he sees a lot of benefits while for Sharon it is a struggle.

### 5.3.3 View of past self and future self

Many people find it hard to accept their HIV positive status. After you test HIV positive, you are likely to experience a lot of emotions and negative thoughts, the major one is the fear of death. From the discovery of HIV positive status to moving on with your life, one had to go through self dialogue that would involve denial, anger, bargaining, depression and lastly acceptance (Brion et al, 2013). Testing positive for HIV often leaves a person overwhelmed with questions and concerns of the past and future behaviours. HIV positive patients tend to link their HIV positive status with their past decisions and behaviours, and also plan their future around their HIV positive status. Letting go of the past, did not erase what happened, but it allows you to lessen and eliminate the pain of the past. It allows you to view that pain in perspective and to accept the pain that those mistakes have caused you. More importantly, the pain from your past no longer dictates how you live in the present and can no longer determine your future.

#### 5.3.3.1 Relationship with the deceased partner

The surviving HIV positive spouses who lose their partners to death through HIV related illnesses tend to remain stuck to their deceased partners due to the HIV stigma. The survival guilt keeps them connected to late partners. They are left with questions needing answers from their late partners and sometimes holding answers to unasked questions from their late loved ones.

Matunzeni had this to say:

*My husband was and is my husband, best friend and soul mate. He passed 5 years ago. My husband has slipped physically out of sight. He is still with me spiritually. He always was. I am not going to go into all the details so personal however his passing though unexpected, even though he wasn't a well man, was perfect and beautiful with me by his side. Everything that was needed to be said was and still is……*

Thando added this:

*Death ended my husband's life. It did not end our marriage and relationship. In many ways I have my well husband back as I can hear the advice and things he would say to me clearly. He is the love of my life. There is no substitute. There never was. I was blessed to be with him. I wanted to spend the rest of my life with him. I have realised that he spent his physical life with me. I only ever talk about him being physically gone as spiritually he has never left me and never. I will always grieve……. Mmmmmh…. The sun will never be quite bright again. I am moving forward with my husband in spirit. He is still part of my life in a different way. I treasure the spiritual moments when I look at his picture……. His death did not take with him all he was and is to us ……..*

Holding onto the deceased loved ones was, at one point in history, considered pathological. Remnants of this mindset can still be found in the attitudes and expectations of our society, but when we accept that we can have fluid, changing, and long term relationships with those who have died, we open ourselves up to a new understanding of grief (Bunnell et al., 2007). A conceptualisation that normalises experiencing grief and sadness years after the death and which gives us permission to continuously redefine our relationships with the person who has died for as long as we live. The above excerpts show that the participants are still stuck to their late loved ones as Thando sees herself as a married person, and this view is detrimental to any effort of letting go and moving on with life.

5.3.3.2 Remarriage

Some people adjust to the end of a marriage and move on to other relationships reasonably quickly and easily, but being HIV positive is in many a confounding variable to a remarriage. In this situation, many may experience difficulties in establishing a successful relationship, given their past experience. The thought of remarrying will always trigger the emotions of being HIV positive and what it is to be HIV positive and thereby interfering with the normal process of marriage.

Mncedisi had this to say:

*I am no longer interested in remarrying and I am too old to be thinking of marriage……. the children I have are enough…… ….mmmmmmh to me marriage is about children so if you have*

*them then …….aaaah there is no need to be worried…..and look I am already HIV positive ……..who on earth would enter into marriage with a dying man……..no one would …..Let me deal with my disease and leave others to their lives…….that way I will have a peaceful death…..*

Matika says:

*I am old now (laughs) I can't remarry. Mmmmmmmh….. New marriage no…no….mmmmh maybe some years but I am not thinking about that……..being HIV positive …..how do you marry sure…..(laughs….) who? How? I think it is unfair to my children to remarry…….I don't see myself marrying……*

Sharon added this:

*Six years have gone without marriage….I don't even dream of this…. I am what I am now because of marriage ……I still blame myself for my past marriage…..and this marriage thing will affect my child …..I don't want that…….I am quite fine with what I have and don't want to create problems for myself and my child …….*

Derek says:

*I think I can get married…..I am still young but I want to respect my late wife……mmmmmh I need a woman who will love me and take care of my children…….you see these children are still young they need a mother…..(laughs)……if I get someone I will tell her about my HIV status right from the beginning……..I think I was a good husband…..I have grown now and I have learnt a lot from this life…….yes remarriage has a room in my heart……I know it will not be easy especially when I get someone who is HIV negative ……..so I would be happier if I get someone who is also HIV positive like me ……..*

Being HIV positive is a key factor in entertaining the thoughts of remarrying and also the attachment to the late spouse plays a pivotal in remarrying thoughts. Considerations include coming to terms with the end of the previous relationship, in this case death as a result of HIV related diseases, emotions of the previous marriage and self-confidence. Remarrying can bring up unresolved feelings from the previous marriage for both adults and children (Maphosa & Maphosa, 2014). Past experiences and relationships influence our choice of who we re-partner

with. Children also play a pivotal role in deciding whether to remarry or not in the cases of Sharon and Derek where their decisions are anchored on children's welfare.

5.3.3.3Relationship with children

Children are a source of motivation for many parents to work and live for. Seeing their children grow makes parents happy and brings a sense of life and of being to them and, above all, purpose of life. The sense of dying and leaving their children young is very scary to many parents and being HIV positive complicates relationships between parents and their children (Maphosa & Maphosa, 2014). HIV positive individuals struggle with what, when, and how to disclose their HIV positive status to their children. Non-disclosure had been justified by parents based on the premise of protecting children from the negative social and psychological consequences caused by disclosure. Some parents disclose and discuss their HIV status with their children as a measure to protect them from acquiring HIV. The excerpts below from participants show some encountered relationships:

Thando had this to say:

*I haven't told my children because they are young!! I relate very well with them but they keeping asking where their father is because they play with some children who stay with their father…. Yes that troubles me a bit…..how to answer this question is always difficult for me…..well I try to avoid the situations where we end up discussing their father…….*

Mafana had this to say:

*My children are everything to me……I am here for them .....remember I once attempted to commit suicide but I failed because of my children…..I am living for these children and don't want to see them suffer or even them to wish their mother was alive due to the fact that they was suffering….I am very protective of them…… it had never been easy…..since my wife passed on…..I told my children, they know everything and they help me take my drugs……when I am travelling they remind me not to forget my medication…..they have been so helpful…..we discuss a lot about the issues of HIV as a family….I want my children to live an honest life that I failed to live myself…….so I have made it my policy that I would not have secrets in my home…….*

Nhlanhla added this:

*I drive my strength from my children…..they are still young …I don't discuss HIV issues with them but I am working hard to fend for them….they are now my responsibility, I don't want them to suffer……My children are a source of motivation in my life…as you can see they need to go to school and it is my sole duty to make sure they don't think much about their late mother…. I have to make sure they get all what is required for them to live very well like other children that have their mothers……*

The findings indicate that parents have a different approach to dealing with HIV issues when it comes to their children. Age appears to play a pivotal role in this relationship because many parents preferred to discuss with older children who have reached the dating age concerning issues of HIV. The presence of children looks like it is an added motivation for living and adherence to medication among the HIV positive surviving spouses.

### 5.3.4 Forgiveness as a way of moving on

One of the greatest abilities that we possess as human beings is the power of forgiveness. Doolittle et al. (2016) argued that people seem to be willing to forgive the transgressions against them but are often unable to forgive themselves. Many are stuck at blaming themselves for the past wrong they might have done years back and failing to move on as a result. Forgiveness can be as simple as moving past issues that barely affect us, to what I believe is the greatest forgiveness possible: forgiving yourself for whatever role you played in becoming HIV positive. Forgiveness is not forgetting, the real goal is not to forget the past, but to learn from it and to use that knowledge to help yourself and others see the world from an informed position. It is very important for one to locate his/her position in the past and present for him/her to self-forgive. Knowledge plays a pivotal role in forgiveness; you need to be clear on what happened in the past, in your stay in the past, your choices in life and your present situation for you to truly forgive yourself and others.

#### 5.3.4.1 Life choices in forgiveness

There are many reasons why some relationships become long distance; however, most of them are due to work commitment by one of the spouses. Fitness (2001) suggests that one of the myths around long distance relationships is that they are always or more likely to fail than other kinds of relationships. However, there is actually no evidence to suggest that this is true; the threat is

that these relationships are at risk of HIV. The couples have to make choices as to what to do in terms of their lives, stay together or live separate but keep the marriage. The greatest risk for HIV infection in marriage is extramarital sexual activities. Magweni et al. (2015) observed that evidence from these research findings shows that sexual intercourse within marriage puts partners at risk of HIV infection, most commonly from their partners' extramarital liaisons. Factors such as labour migration involving the separation of spouses exacerbate partners' HIV vulnerability.

Nhlanhla had this to say:

*I was working in South Africa and my wife was here at home in Zimbabwe, I would go home say thrice a year……. When in South Africa, I would have casual sex with different women…. I did not know much about HIV and never used protection……There were rumours making rounds that my wife was involved in love affairs with a local school-teacher…… never took it seriously…..But you see these things add up at the end ….my wife was the first to test HIV positive before me ……when I learnt of it I was so angry because I thought of the teacher who was talked of some time ago…….well the issue was this long distance marriage….we were never together with my wife …married yes….but we never stayed together……..this is the result….*

Matunzeni had this to say:

*My husband was working at a Mine far away from our rural home….he was a good man truly and you know with these good and nice men…..you are not the only one who is interested in them. I think women could have seduced my husband at his work place to have engaged into casual sex especially with the life in the mines…….I wish I could have stayed with my husband…..eish…these things come unexpectedly you just find yourself in this mess …… whatever happened to my husband…. I don't know for sure…but I know he loved us…..it was this long distance relationship that put my man in trouble……I know him…..well men with women…. It is always a problem……*

Thando added this:

*You know I got married when I was just 23 years old…..you see I was very young ….tell me …my husband was working in South Africa……what did you expect me to do….I was very lonely*

*…mmmmmh…you might not understand …don't judge me please… I felt very lonely... imagine newlywed and your husband disappears to another country….. I was at my prime years to be with my husband ……so that I could enjoy life… but here I was alone….. I fell to some temptations and had an affair…..everything went wrong I suppose…..well I don't blame my husband….I think about …if we had stayed together maybe we could be talking a different story now….. I blame the distance…..this distance created all what I am in now……..*

Adonis (2015) argues that research findings show that long distance relationships are a great risk in HIV infection among the married couples. The use of protection is seldom used among the married because the talk of protection raises questions of infidelity and lack of trust, hence, partners prefer not even to talk about it. These choices are not easy to make, money is needed at home and one has to go to work and the other one remains behind maintaining the home. As I look at Matunzeni and Thando's excerpts, there is some rationalisation towards forgiveness as they justify the possibilities of acquiring HIV.

People living with HIV can lead a full and healthy life. They can have sex, have children, work, play sport and make plans for the future. When people have HIV they have to make choices and accept some responsibility to protect their own health, and the health of others. If you have been diagnosed with HIV, it means that you were exposed to the virus and a test has shown that you are now living with HIV in your body. It is important to know that there is nothing wrong about you, it is only that you have acquired the virus from someone and sometimes you might not know how, and from who and when. It is very important to be very careful with your choices be it mental health, disclosure, protecting others against acquiring HIV, dealing with stigma and discrimination, family planning and healthy living with HIV.

Matika had this to say:

*When I look at my past, I realise now that I made a lot of wrong choices……I had sex with people without protection…..I was very casual with life…..if I had gone for HIV test at an earlier time maybe I could have saved my husband…..Now that I have gone through all this I know what I want from life……..life is about choices that you make……it is very important to think hard for whatever you want to do so that you do the right thing……. I am very careful with my choices*

*because they mean a lot to my children…….I watch my health closely for the sake of my children…..*

Thando added this:

*I regret my past behaviours……all this that I am experiencing is as a result of what I did in the past…..I have seen life…..Maybe if I had told him that I was not happy with his going to South Africa….maybe it could have helped……then I never realised that I was making wrong choices….now I take my time to make a decision……I want to go back to school but you see…… I am saving money for my fees I am trying to make good decisions that will not disadvantage my children……..My HIV medication is my first priority always adherence is not a problem because that is my life…….*

Nhlanhla had this to say:

*I think both of us my wife and I put our lives at risk through this long distance relationship ….we failed to communicate properly we left everything to chance…..our choices put us in this problem. I wish I had gone with my wife to South Africa. I think people like my mother are good in making choices in life…..look how old she is but taking care of my children, without her I could be suffering….I have promised myself to live positively with HIV until I see my children graduate from colleges…….I do think of marrying but I must be sure and be ready as you know I am HIV positive……I think I need to be prepared for anything I want to do now….choices matter in life……*

Adonis (2015) argues that research findings indicate that life choices play a pivotal role to an individual's life, especially to those who are living with HIV. It is very important that they dialogue within themselves before they engage in an activity in their lives be it travel, investment in business, saving for school, seeking treatment or planning to marry. There is need for the surviving HIV positive spouses to find a health care team that is knowledgeable about HIV care that would assist in decision-making because any decision taken or to be taken should be in cognisance of HIV positive status.

5.3.4.2 Turning to God

One of the reasons people judge those who are living with HIV is that the disease is related to sex. Living with HIV is often associated with sexual immorality, promiscuity and a curse by God. Testing positive for HIV often leaves a person overwhelmed with questions and concerns. It is important to remember that HIV is a manageable disease that can be treated with HIV medicines, (Bunnell et al., 2007). HIV medicines cannot cure HIV, but they help people living with HIV live longer, healthier lives and reduce the risk of HIV transmission. But with all these assurances, the shock is such that often, for the person, it still felt like a kind of death sentence. HIV diagnosis seriously disrupts a person's life. It can take many years to come to terms with HIV. The surviving HIV positive spouses are worsened by the loss of their partners.

Percy had this to say:

*I believed that people who contract HIV were the prostitutes and people like me who go to church were very safe…..was very disappointed and embarrassed……how would people at church look at me…….I wanted even to leave the church as a result of my HIV positive status…… I prayed daily for forgiveness from God…….. I always ask God to reveal to me what wrong I have done to Him to deserve this disease……..God had answered some of questions and request…. I have let go the anger I had for my husband……I am getting a lot of help from the church…….members come to home sometimes to assist…….However, some are still not comfortable with an HIV positive person…….you can tell that they are not comfortable tobe next to you…….especially due to the relationship that exist between the HIV and immorality. Yes the church is trying to correct itself of blaming HIV positive people so that stigma and discrimination should not be at the church…..as for me I have my God by my side……*

Sharon had this to say:

*My faith is keeping me going. I have faith in my God. God had a reason for doing this to me……I grew up a good girl hoping to get married to the best man of my life……Got married but look what I got …….I think it is God's design that I go through this……I have put everything in God's hands…..I pray to live longer and see my daughter go through her schooling……..*

Derek added this:

*The death of my wife brought me close to God……*

Mafana had this to say:

*My wife trusted me so much as we were people who were highly respected in the church……I have a troubled heart and pray daily to God to forgive me for my sins…….come to God daily confessing my sins……..*

Pastoral and spiritual support is vital. People living with HIV need reassurance, encouragement and acceptance from their Church. HIV in Church raises uncomfortable issues such as anxieties around sex, sexuality, disease and sin. The contours of the struggle to make sense of intimacy with God, oneself and others after HIV, become familiar. Relationship and sexual intimacy come into question, perhaps with particular issues around immorality, disease and death. Christian life is lived only in a community of faith. How did the Church treat and view people living with HIV. Can the Church be trusted to accompany people living with HIV? These are issues that made participants turn to God for God does not judge them unlike other church members who showed attitudes and tendencies of stigma and discrimination.

5.3.4.3 Forgiving and Moving on

A journey that began with a wedding ends with a "moving on." A lot had happened in-between transforming a young HIV negative person into an old new surviving HIV positive spouse, who is forgiving and moving on. Forgiveness, reconciliation and reconstruction of a new person who had come out of happy marriage, blessings of healthy children, disappointment of testing HIV positive, to being a caregiver for an HIV positive spouse, to being a chief mourner, to widow, widower and finally to forgiving and moving on.

Sharon had this to say:

*I have learnt that we have to accept what has happened in life and find a reason why it happened and be at peace with the reason. I have been a single mother for the past 6 years…..I think I am doing well, I can live with my daughter and I am at peace with my medication ….as you can see you can't tell that I am HIV positive…….I am working trying to raise funds to further my education…..I think I am fine with my life……*

Methembe had this to say:

*Life is a great teacher, I have learnt that it is very important to share your problems with your spouse……I sometimes blame both of us for failing to discuss and share our problems…..I have many questions that are unanswered…… I think I don't have any future as things stand nothing is moving in my life…….you see we lost our only child and now I am just alone here….what do I do……beside drinking beers all day…eish but I don't forget to take my medication…..life has never been good to me….I might have done something that angered my ancestors because all my things are complicated……..*

Nhlanhla added this:

*I am always wondering about how this thing came home…….I am sometimes confused indeed….I haven't forgiven myself and my wife no no I haven't…….I am looking after my children but I am still stuck…..why my wife…….*

Matunzeni had this to say:

*I don't trust men anymore ……My sons are grown up now and I am able to fend for myself….I am not very sure about forgiving my husband but I am no longer angry now…..I think I have managed to move on with my life……..*

Mafana had this to say:

*I haven't forgiven myself……I think about my wife everyday…… I attend HIV organisations and at my church they try to offer us some help and counselling but I think I am stuck….I have so many questions and issues to discuss with my wife but eish……..*

Derek says:

*I am still in the process of healing…..I go for counselling sessions ….I hope one day I will be fine….. I am still young when I have fully recovered I might get married again but for now I think I am still mourning my wife……*

From the research findings the surviving HIV positive spouses find it difficult to forgive and move on, they are stuck on what might have happened to them or to their late spouses. When a person moves on, that person is going beyond the situation, trying not to let what happened influence emotions, thoughts or behaviours in the present, (Hallfors et al., 2016). Most of the

participants are still preoccupied by the death of their spouses indicating that they have not moved on at all. To forgive is to offer a moral virtue of mercy to someone who treated the forgiver poorly, focusing on the other. Forgiveness moves towards the offender through kindness and generosity in the hope that the other will change. The motivation in moving on is to look forward, to get on with one's own life, whether or not that includes the offending person. However, when you forgive, the focus is on the other; when you move on, the focus is on the self. Forgiveness actually helps a person move on. The participants have not achieved both in their case.

### 5.4 Chapter Summary

The self-identity track reveals that HIV brings pain in the otherwise good and healthy families. Relationship with significant others changes dramatically right from testing HIV positive into the after the death of the other spouse. There are regrets in the view of the past self and a seemingly gloom future self. Most of the participants failed to forgive themselves and their late partners thereby making it difficult for them to move on with their lives.

# CHAPTER SIX
# DISCUSSION

## 6.1 Introduction

The flow of this discussion is anchored on the four master themes, namely, life with HIV in self-identity track, relationship with significant others in self-identity track, view of past self and future self in self-identity track, and forgiveness as a way of moving on in self-identity track. Losing a spouse to death through HIV related illness and being HIV positive could devastate and alter the way in which an individual perceives him/herself. Following this, an individual could require reconstruction of the self after the mourning period is over. Self-identity reconstruction could require a deep dialogical self that would provide an insightful framework for understanding what has happened (the death of the spouse and being HIV positive). This chapter will be premised on the discussion of the findings guided by the dialogical self theory.

## 6.2 Life with HIV in Self-identity track

Stanghor (2013) argues that self-identity stems from differences that we have as individuals in the context of others; a concept that is not static, always changing to suit the demands dictated by the requirements of survival. Identity is fluid. We are each many things, a product of our past, present and future. Our identity is multifaceted and distinctly our own. The surviving HIV positive spouses were and shall always be a product of early life values, marriage life, their HIV positive status, stigma and discrimination, death of their partner and living without their spouse. Self-identity reconstruction is not a one point moment event, but a life of changes and adaptation. The identity of people living with HIV is fluid and non-linear as was observed by Moses and Tomlinson (2013). They purported that people living with HIV are always sensitive to their conduct, thereby affecting the way they would behave; this they argue is because HIV is viewed as a sign of loose behaviour. Hareb (2011) alleges that people thought that people living with HIV had a spoiled self. The spoiled self emanated as the hated, disgraced, and undermined and discriminated self that individuals within the community despised.

Elliot (2013) posits that early life values tend to shape what we become as the world is perceived through what is known to our being. The world becomes what you think it to be and what you perceive; and perception is a product of our experiences in life. Elliot (2013) further argues that instilled life values at a tender age become your tools for recovery at a later age in life after

coming across life threatening events. Our upbringing and socialisation have a huge impact on our perception of the world as it was observed from the participants' views. Evans (2015) argued that men grew up expected to be seen as strong men who relate with sex in a casual way and who should get involved in sexual activities at an early age for them to gain experience for their marriage. A man was expected to get married after having dated and had had sex with a lot of girls to show prowess in his sexuality. Virginity was shunned among men but glorified among women.

Early life values tended to revisit individuals when problems arise at a late stage of life. The narratives from males show that their carelessness towards sex was inculcated at a young age. Kross et al. (2014) observed that the knowledge of the self was enhanced through the mental process of introspection. This kind of dialogical self evaluates the past self in comparison with the current state of self. If in the evaluation the past is regrettable, the current identity becomes self-pity. In the same vein, if the early life values were upright, the perception of oneself in the dialogical self can dramatically reduce self-esteem when one discovers that he/she is HIV positive. In this study Sharon and Percy were disappointed by being HIV positive and suspected that their husbands brought this virus to them and that their wait for a good husband was in vain. This kind of disappointment interferes with identity reconstruction as they live in perpetual regret instead of paying attention to the future.

The eventuality of being HIV positive is then viewed as a punishment of being good as observed by Sharon and Percy. The question that becomes difficult in self-talk would be why them, when they kept themselves good for their marriage. Schwarzer (2014) propounds that self-inspection helps an individual to develop a sense of self-identity through an inference into their past behaviours. The participants did not acquire HIV at an early age, but the early life age behaviours occupied their self-talk about their current HIV positive status. Those that perceived their early life behaviours as bad always blamed and regretted those years that might have brought bad values and behaviours into their lives which resulted in being HIV positive. Good behaviour in early life was seen as not paying any dividends if anyone could be HIV positive.

Kposowa (2013) observed that individuals who are in a marriage alliance are at a great risk of acquiring HIV. In marriage partners are likely to relax in the comfort of faithfulness, as they both believe that their being at risk of acquiring HIV ceased on the wedding day. However, those that

are involved in infidelity might fear to suggest the use of protection during sexual intercourse in fear of being suspected of infidelity. Fear of being suspected of infidelity leaves the other spouse at a high risk of being infected with HIV. Zakaras (2017) found out that there were negative attitudes towards condom use within marriage placing individuals at a great risk of HIV infection. Living a life that is an envy of many creates a flawless perception of 'purity' and this has a huge negative effect on self-identity reconstruction for an individual who is HIV positive. The fact that married people are not supposed to be of loose morals. In their self-talk, the surviving HIV positive spouses see themselves in the eyes of their village as having been involved in extramarital sexual relations. Epstule and Jonas (2014) argue that HIV permeates the marital system easily, as the major means of prevention against HIV are not readily acceptable for married individuals. Being diagnosed HIV positive is a life shattering experience and has a great bearing in an individual's reconstruction of self-identity. Maphosa et al. (2017) found out that marital unions, unless stated otherwise, carry the expectation of intimate and sexual exclusivity between the parties within the marriage alliance. Hence, no one is expected to be HIV positive when he/she got married HIV negative and any contrary reflects loose morals. Straube (2013) discusses how couples who immediately embrace the reality of their situation and adopt an alternative lifestyle that strengthens positive health outcomes have a greater chance of living fulfilling lives where they can set lifelong goals together and attain them. The participants are either angry at themselves or their late spouses. Finding out that one is HIV positive changes one's life completely as indicated by Matunzeni's sentiments. The reaction to the diagnosis of HIV positive has some lasting effects and the effects have great influence in the reconstruction of self-identity. Individuals should note that their reactions should not mark a permanent scar that would be difficult to erase in a bid to reconstruct their self-identity. However, Epstule and Jonas (2014) argue that the expectations for marriage make it difficult to easily accept being HIV positive and being perceived as a spoiled self is a huge connotation that creates animosity between couples. When one looks at the reaction of Nhlanhla, who was working in South Africa then, shows some regret later and as a result got stuck in the process of reconstruction of self-identity. Self-identity reconstruction includes conciliation, reconciliation, disclosing and forgiving and then moving on with your life.

The process of identity transformation from spoiled self to a reconstructed self-identity happens when one is at peace in the dialogical self. This means that reconstruction of self should begin

right at the diagnosis of HIV positive status. Goffman (2009) identified that the spoiled self was characterised by negative attitudes towards the self in the self-talk, labels that identified one of the partners as the cause of the disease in the family. The labels have a negative impact on an individual's reconstruction of self-identity as these thoughts keep coming up as one is trying to move on with life. The participants reported stigma and discrimination from their families and community at large. This, therefore, means that as the surviving HIV positive spouses are trying to reconstruct their self-identity, challenges from their society make it difficult. The HIV positive individuals also create within themselves a perception that they are victims of unfortunate circumstances that led them to their being HIV positive. The self pity and self-discussion within an individual who is HIV positive creates more vulnerability to the perception of being damaged. Dube (2016) and Sleap (2001) argued that the society might not be shunning the individuals who are HIV positive but the individuals who are HIV positive create all these in their self-talk and end up believing their self- dialogue.

Too much worry about yourself and the society's perception about yourself create an illusion of perceived stigma and discrimination. This is a point also noted by Goffman (2009) who argued that being HIV positive triggered individuals to discriminate and stigmatise themselves. This was apparent in self-pity and self-isolation among the participants. Most of the participants turned to God and declared that the only source they trusted was God. This has implications that all people around them are not to be trusted, which on its own is discriminatory. Real or perceived stigma and discrimination has negative effects on self-identity reconstruction as it hinders the acceptance of one's current condition of being HIV positive thereby making it difficult for an HIV positive person to move on with life.

Caring for the ill spouse might be a complicated task to take on, especially if there are unresolved feelings of anger and blame for the spouse believed to have brought HIV in the home. It is this thinking of Mafana, as a surviving HIV positive spouse, that would forever interfere with proper recovery and reconstruction of a self-identity. Mafana might harbour feelings of loathing and, in turn, be stuck in self-blame for a long time without any progress for reconciliation, reconstruction and forgiveness. Methembe is left wondering about what the world has for him as he watches his spouse dying in front of his eyes. Watching your beloved one being ill and searching for answers of what could have happened and what wrong you could have

committed, creates self-blame in one's self-talk. It is this, then that acts as a barrier in one's thoughts in the reconstruction of self-identity. The behaviours that are shown during the illness of your partner remain in one's mind long after the partner is dead. These behaviours and feelings remain forever in the self-dialogue and have a tendency to direct the reconstruction of self-identity.

The spouses living with an HIV positive person often need help themselves to come to terms with their own fears and prejudices as well as implications and consequences of their loved one's sickness and ultimate death. Pryor and Reeder (2015) argue that HIV puts the burden of care on the affected that will be grappling with the impact of HIV infection as they will be experiencing fears and anxiety about their own risk of infection, and are often angry with the infected person for bringing this onto them. Having a loved one diagnosed with HIV often affects the family's ability to cope as they are anxious and struggle to cope with their circumstances. Pryor and Reeder (2015) further argue that the spouses often feel unable to cope with the new demands that the infection places on them leaving feelings of incompetency, being unqualified and powerless in their interaction with the HIV positive partner. As a result of the home based care initiatives, the affected often have to care for the loved ones, fulfilling a caring role for which they are not trained. They may feel that they are already losing their loved ones and this can precipitate an early grieving process.

Ross (2011) observed that most individuals that had lost a loved one to HIV went through a series of deliberations that shaped their overall impression on the implications of the pandemic on their lives. Ross (2011) further suggested that the surviving HIV positive spouses go through the grieving stages before eventually accepting their statuses. The above sentiments show the survival guilt within the surviving HIV positive spouses. These make the reconstruction of self-identity difficult as an individual would be failing to face reality that one is HIV positive and that the partner has died. The surviving HIV positive spouses are trapped in the spoiled self, that inwardly they are trying to reject and outwardly they are trying to accept. Evans (2015) posits that secrets about the source of HIV and death can impact on the bereavement process causing anxiety and nervousness to the spouse. The surviving HIV positive spouse faces the dilemma of whether to disclose the nature of the illness and cause of death to the children.

Sleap (2001) argues that HIV is characterised by periods of fluctuating health and illness, if the surviving spouse is unable to disclose to the children, tensions often emerge about hospital visits, medication and fluctuating health. By ascribing to themselves the responsibility for the death of their partners, the surviving spouses block the reconstruction of a new self. The death of a loved one is a permanent scar that the surviving HIV positive spouse has to carry for life. The situation is worsened by the fact that the partner died of HIV related illness and the surviving spouse is HIV positive. Both Percy and Mncedisi have unanswered questions which they have to continuously contend with. These unanswered questions make it difficult for the reconstruction of a new self. Briggs (2012) noted that in the face of shame, guilty and anger, the surviving HIV positive spouses would redirect their energy towards securing a good future for their children. Life without a partner was full of regret, torture, stigma and discrimination. The meaning of life and reasons for living change, and the focus becomes the children.

There were psychological impartations on the surviving HIV positive spouses such as anticipation of new intimate partner on the self and anticipated use of condoms with the new partner. There were issues to do with fending for the family alone, taking care of children and learning the roles of the deceased partner in order to complement the home. Some of the surviving HIV positive spouses got support from their parents and church organisations. Life without a spouse, to many remained a problematic terrain to navigate as there were perpetual reminders that they were to follow their deceased partners due to their being HIV positive. Participants felt that the fact that their partners had died of HIV related illnesses and that they themselves are HIV positive was a binding factor for life, their fluctuating health and medication to be taken always acted as reminders that their partners had died. It is this kind of perception that makes it difficult to reconstruct a new self as one gets stuck to the past events.

### 6.3 Relationship with significant others in Self-identity track

Significant others are people who form the key environment of an individual. They may be perceived as an extension of who the person is their actions, reactions, emotions and the way in which they approach life. What they say, feel, think and do has a short or long impact on the person’s life and might motivate or demotivate, encourage or discourage one’s actions and decisions in life. In the centre of the argument here, is a surviving HIV positive spouse. Accepting one’s HIV positive status hinges on the support system one has in the form of

significant others. Dube (2016) argues that the key components from the significant others are the elements of disclosure, their reactions to finding out about the HIV positive status, and their presence as an individual goes through life changing events.

Hypothetically, rewards of disclosing one's HIV positive status are many, and can lead into the attainment of numerous resources. These resources may be emotional, physical or social in nature. For example, emotional benefits might include the acquisition of social support, relief from sharing a burdensome secret, and the intrinsic reward of educating others about HIV. Disclosure of one's HIV positive status to sex partners has been found to lower infection rates as persons may be motivated to engage in or adapt safer sex practices (Van Dyk & Van Dyk, 2003). The above sentiments show the difficulty faced by the HIV positive people in terms of disclosure. Reactions from the significant others are a deterrent to disclosure as the fear of being rejected, shunned or even shamed engulfs one's thoughts as in the case of Matika and Nhlanhla. Learning that one is HIV positive creates an internal struggle about whether or not to disclose one's HIV positive status to others. Sleap (2001) posits that the decision to disclose is selective and consists of several steps, including adjusting to the diagnosis, assessing one's disclosure skills, deciding on who to tell, evaluating the recipient's circumstances, anticipating the recipient's reaction and having a motivation to disclose. The decision to disclose one's status is a difficult one, and must include to whom, when, where, and how to reveal one's HIV positive status to others. Hence, it was difficult for the participants to disclose to their significant others. The delay in disclosure involved a careful, reasoned evaluation of the risks and benefits for oneself and significant others when disclosing one's diagnosis of HIV.

However, Sleap (2001) further argues that the reasons for not disclosing include the following: stigma and discrimination; need for privacy, fear of rejection by significant others, threat to personal well-being, potential loss of income, and difficulty in communicating, denial and personal characteristics. Living a life full of secrets is a daunting task that is likely to act as a barrier to the reconstruction of a new self. It would be difficult for an individual to live positively with HIV positive status without full disclosure. It is when one is free to talk about HIV positive status, free to access medication, free to learn more about HIV and free to disclose to significant others that one begins to live positively with being HIV positive.

Dube (2016) argues that the reaction of one's significant others to their HIV positive status is of significance to charting a new life and new self. People react differently; others might react negatively while others might react positively and in acceptance of your situation. Sleap (2001) observes that the disclosure of HIV positive status has potential risks such as blame, divorce, abandonment, physical and emotional abuse, stigma and discrimination. The reaction to disclosure can lead to break-ups of marriage, loss of shelter, loss of relationships or even suicides. The sentiments from Methembe and Sharon are a testimony that disclosure to significant others is a complex endeavour as one can never pre-empt what the reaction would be. The negative reaction towards testing HIV positive by sexual partners, children, friends and other family members has a negative impact on the reconstruction of a new self. Negative reactions create stigma and discrimination which further alienates the HIV positive persons. HIV is not a disease, and if properly managed and having supportive environment, one is able to live longer and die without having developed to full blown AIDS. However, this calls for support from significant others.

The relationships with significant others play a pivotal role in an individual who has tested HIV positive. Evans (2015) argues that the strength of the inner self is anchored on the views, attitudes and behaviours of the significant others towards the HIV positive person. Learning that one is HIV infected creates an internal struggle that tries to resolve what the outside world is saying about being HIV positive and the inner self's personal evaluation. It is these debates that take place in the self-talk that would pave the way for the reconstruction of a new self. This process of reconstruction of a new self involves dialogical self which needs the understanding of the person shift (Irish, 2014). The self has moved positions, one who was happily married and has suddenly become a single parent, widower, widow and has just become HIV positive. The transition from one person to another person within an individual requires a strong supportive environment from the significant others.

Surlis and Hyde (2001) observed that is some blame game after the death of one's partner from family members and the accused is usually the surviving spouse. This gives the surviving HIV positive spouse a hard time to prove her/his innocence on the issue of being responsible for the death of a partner. This is likely to develop into survival guilt where the surviving spouse believes that she/he is partly to blame for the death of his/her partner. Derlega et al. (2008)

further observed that negative emotions and the need for catharsis found the surviving spouse as the only source of blame to why and how HIV affected their loved one. As the other spouse is not around to answer questions from demanding significant others, the surviving spouse has to be the one answerable to what might have transpired. Failure to give answers to significant others could be interpreted as trying to hide the source of HIV by the surviving HIV positive spouse. Illness has the capacity of shaking the family system and can create anger among family members, thereby creating a weak support system.

Irish (2014) argues that human health is tied to a sense of connection to social environment. The blame game and the search for the source of HIV have a great potential to worsen the patient's illness. Support from significant others is the key in the healing process. The HIV positive patient should not be made to feel guilty of what has happened to them. The feeling of guilt destroys them completely as they blame themselves for the death of their loved one as if they are responsible for their death. This also hinders their recovery process and trying to search for the evidence to defend themselves and prove to the world that they are innocent. Irish (2014) further argues that social integration can facilitate reconnecting HIV positive spouse with their community through social activities, improving their self-esteem and strengthening the sense of belonging.

This interaction between the HIV positive spouses helps the healing process for both the sick spouse and the caring spouse. It is at this point that the surviving HIV positive spouse should start the reconstruction of a new self. Mafana epitomises that approach as he was getting all the support from the family including his children who were grown up and were able to understand HIV related illness and could also appreciate their mother's illness. This understanding and cooperation from the family helped Mafana to adjust easily to his new person even after the death of his wife. Methembe is also left alone, but he does not become lonely because of the family support system. It is when one realises that he/she is not alone in this world that one begins to chart the way forward. The self-talk of an individual who is accepted and embraced by significant others is highly positive and is likely to lead to a positive self-regard. Support from significant others, no matter how small it might appear, has a huge impact on the outcome of a good behaviour. It is this resultant good behaviour and positive outlook of the world that helps individuals to live positively with being HIV positive.

### 6.4 View of past self and possible future self in self-identity track

The self is an elusive concept which is never static as it keeps changing to fit or adjust to the ever changing environment. As human beings grow up, learn new material, discover more in the world, the self cannot remain behind, the self has to grow also to meet new demands of the world. HIV has changed the human dimensions in all aspects of life such as view of the past, current and possible future selves, and as a result, these multidimensional levels of life have to be understood in their connectedness nature. As those affected and infected review their past and plan possible futures, it is critical to create spaces for dialogues within ourselves and with each other about the implications of HIV in our lives. I argue in this research that the surviving HIV positive spouses are always involved in self-conversations, and in these conversations they review their past, current and possible future now that they are HIV positive and what it means to them and their significant others. In this journey of their dialogical self, they review their past as regrets from past events; they review their relationships with their children in relation to their current HIV positive status; and the entertainment of the thoughts of remarrying.

Humans usually look back into their past lives for them to plan for their possible future. The current self is always a product of how one views the past self in conjunction with how one views the possible future self. Peta (2017) stated that some spouses remained in the marriages even though they knew that their partners were suspected to be involved in extra-marital affairs. Remaining in this kind of marriage knowing the dangers that are likely to befall you is a reason to regret in the near future. Pryor and Reeder (2015) argue that humans are endowed with reasoning capabilities and are able to predict the future based on the current behaviours or even suspected behaviours. It is, therefore, pertinent to attempt to get an understanding of the decision-making processes people go through and the implications of such decisions. This study highlighted the regret by most of the participants when it comes to their past choices and the implications of these in the present.

The elements of distrust and betrayal from their trusted partners brought about a lot of regrets and a bleak possible future. In their self-talk, regrets become a dominating thought that hinder any positive development. Sharon, Matika and Mafana seem to be apportioning a lot of blame to their past selves and the choices they made. This blame is contributing towards the difficulty they seem to be experiencing in their present selves and in imagining possible future selves. .

To many parents, children represent an extension of their being, and are a reflection of who they are and, as a result, they strive for the best for their children. Children often view their parents as perfect beings who have answers and are without faults. Paulos (2011) observed that the major problem associated with HIV among the spouses was explaining the illness or death to their children. Epstule and Jonas (2014) argue that the situation becomes worse if the other parent dies and the remaining parents have to grieve the death of the loved one with their children and at the same time telling them that he/she has a similar disease. This is also worsened when the children are old and have an idea of how this virus is transmitted most of the time; however, if the children are too young to comprehend, parents might choose not to tell them anything. Failure to explain to her children troubles Thando because she does not want them to discover on their own. She also feels that her children are too young to understand what HIV is all about. This hinders Thando from living positively with her HIV positive status as she constantly worries about her children discovering on their own and the issue of stigma and discrimination that her children could suffer in future.

According to Briggs, (2012) in the face of shame, guilt and anger, the surviving HIV positive spouse survival possibility changes and is directed towards securing a good future for the children. The participants demonstrated a dire need to survive in an attempt to prolong their lives and improve the socio-economic standing of their children. As noted from the other participants, parents who are infected with HIV are also nervous and anxious about their children's ages and maturity. This is a great worry to the parents as they want their children to be taught or to come to know about HIV and if they had the power to decide who teaches their children, they would have found a competent teacher who would guide their children so that they do not find themselves in the same predicament as their parents.

The common concern among the surviving HIV positive spouses was the uncertainty about the right age to disclose to their children; how to explain the diagnosis and the source of infection; the role of the deceased parent; and the fear of the secret being discovered by children on their own. As the surviving HIV positive spouses are grappling with how to relate to their children in their self-talk, this interferes with recovery and reconstruction of a new self that accepts their current condition.

Maphosa and Maphosa (2014) posit that remarriage refers to marrying after the dissolution of the previous marriage, be it through divorce or death. Many of these marriages include partners with children from a previous relationship and it can present challenges to a couple in their relationship as partners, parents and step-parents. Having lost your partner to HIV related illness, and being HIV positive yourself, compound the problems faced in the new relationship. Being HIV positive carries with it stigma and discrimination that would interfere with the establishment of a new relationship in marriage.

Maphosa and Maphosa (2014) further argue that failure to come to terms with your partner's death might lead to difficulties in remarrying. Thando believes that her marriage and relationship with her husband did not die with the death of her husband. She cannot put off her thoughts and emotions of her first marriage. With these emotions she can find it very difficult to reconstruct a new self and move on. In her dialogical self she considers herself still married to her late husband. Worden (2008) observed that the young and sexually active surviving HIV positive spouses would prefer to get married after the death of their spouses. This shows that age plays a role in remarrying after the death of one's partner. Both Mncedisi and Matika cited age as their reason not even thinking about remarrying while Derek who perceived himself as still young also cited age as the reason for considering remarrying as an option. However, in both cases, the HIV positive status featured as a confounding variable as cited also by Hoffman (2013) that transforming from the spoiled identity would always be a difficult process that most young HIV positive widows and widowers find it difficult to remarry. Most participants cited their children as occupying the uppermost place in their hearts rather than considering remarrying. They cited living and working for their children for better life as the most significant thing to their lives. Remarrying was viewed by participants as a problem that could interfere with the parenting of their children and as a problem that was likely to invoke past emotions of how they acquired HIV.

### 6.5 Forgiveness as a way of moving on in self-identity track

Chung (2014) argues that one of the greatest obstacles to working through forgiveness is the hurt, anger and resentment felt by the betrayed partner. These feelings, whatever their roots, need to be openly acknowledged and constructively expressed. Another obstacle is the inability to trust the betrayer, who has typically connived, lied, manipulated, covered up and otherwise

deceived his or her partner. Doolittle et al. (2016) argue that trust is the glue that holds a relationship together, and love alone is not enough. Commitment entails trust: making a promise, a pledge, a choice to say yes to this person and no to any other, and then consistently keeping that promise. Once that pledge to commitment is broken, it becomes difficult to rebuild. The fragile and sacred container or frame of the relationship has been violated and trust has been broken. Doolittle et al. (2016) further argue that broken trust is one of the most difficult dynamics to restore in relationships and without trust, intimacy suffers. When emotional intimacy dries up, so does sexual intimacy. Resentment festers, distance replaces closeness, communication breaks down and hostility kills kindness and caring. The atmosphere turns toxic and relationships slowly disintegrate and die. All this becomes worse if the other partner dies and, worst, if the death is a result of HIV related illness.

Addressing the underlying problems in the relationship in the aftermath of the betrayal can, in some cases, serve to improve communication and strengthen the partnership in the long run (Jones & Musekura, 2014). First, the trust that was broken must be re-established, a delicate process that requires effort, time, motivation and total commitment. Often the act of forgiveness follows after a person who has wronged another asks the person he or she has transgressed against for forgiveness. Forgiveness becomes difficult although possible when the other partner is deceased. Chung (2014) observed that to the person forgiving, forgiveness is a product of internal conversations (dialogical self) that evaluates numerous variables and reaches the conclusion that allows one to forgive. Knowledge plays a pivotal role in the forgiveness process; one must know what he/she is forgiving, the parameters for forgiveness must be clear, and lessons learnt must be very clear so as not to repeat the same action in the near future.

HIV is a virus that can only be passed on in specific ways and these ways do not include physical contact, sharing utensils, and so on. Mills (2017) argues that a number of myths have arisen about how HIV can be transmitted and that understanding how the virus does and does not spread can help prevent not only transmission but also misinformation and ungrounded fears. What has compounded the HIV problem is the belief that the spread of HIV in our society illustrates how immoral we are. The moral questions around HIV are inescapable and carry high validity given the trends of infection and population risk groups. Yet, to brand HIV as purely a

consequence of immorality would miss the complexities of how HIV is spread. Not all infections are a consequence of not adhering to moral standards.

Mills (2017) further argues that the assumption behind the HIV moral dilemma is that the spread of HIV has been facilitated by behaviours which do not meet society's moral standards. It would also imply that the infection dynamics are fuelled by the failure to adhere to the principles that distinguish between right and wrong, good and bad behaviour. It also comes on the assumption that regulating behaviour along stated lines of good and bad will have combated the spread of HIV in our society. Redfern, Barnes and Chang (2016) argue that the spread of HIV amongst humans seems to point out that; indeed, the spread of HIV in our society illustrates how immoral we are.

The moral implications in the spread of HIV apply to the fidelity dynamics within the family set up. Marriage is seen as a buffer for HIV infection (referred to by one of the participants, Sharon), a platform where unprotected sexual intercourse does not carry as much risk as in casual encounters. This is risk, of course, if the moral union is upheld. A marital union of two HIV negative people who uphold the moral standard and moral virtue of fidelity is almost as immune to HIV as any relationship will ever get. HIV, in most instances (like in most participants), permeates into the marital union when fidelity codes are broken and usually HIV is then spread to the other partner. In such an instance, it is clear that the spread of HIV is necessitated by the immorality of persons in our society, adhering to the morality of fidelity would most probably protect partners in the union from being infected by HIV.

However, Barlow (2015) observes that the argument that the spread of HIV in our society illustrates how immoral our society is appears a little misplaced. This is largely because it discounts other modes of transmission which are equally responsible for the spread of HIV (Barlow, 2015). The assumptions that the spread of HIV is linked to immorality are very dangerous and are a particular trend of thoughts that has been common among the participants of this research. Along the same lines, using morality as a reason for the spread of HIV has done little to actually erase the stigma associated with the virus. Peterson and Van Tongeru (2016) argue that viewing HIV strictly in terms of good and bad behaviour has led to those with the virus being shamed for it. It is assumed that if a person is infected with the virus then this must be the consequence of an immoral act. It is assumed that such a person had numerous sex

partners and is often stigmatised for it as the assumed behaviour does not meet social standards of morality.

Shapiro and Ray argue that when a person learns that they are HIV positive it is upsetting, shocking, sometimes hard to believe and stressing and that the shock is such that often, for the person, it feels like a kind of death sentence. HIV diagnosis seriously disrupts a person's life, life will never be the same and it can take many years to come to terms with being HIV positive status. Regalia and Pelucchi (2014) argue that the church is in a unique position to demonstrate the love and grace of God in the midst of HIV pandemic. It is now common knowledge that in HIV, it is not the condition itself that hurts most, but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV positive people have to deal with. It is when the HIV positive people have lost trust and love from their significant others that they turn to God as the only understanding companion.

Regalia and Pelucchi (2014) posit that prayer is about communication with a higher power to express feelings and thoughts, offer gratitude and make requests. The participants in this research alluded to feeling too isolated after losing their spouses to HIV related illness. Having a sense of a higher power (God) that you could communicate with could be very comforting. Regalia and Pelucchi (2014) further argue that when things are not going well, a conversation with a higher power can provide a focus for overcoming negative thoughts and expressing difficult feelings like grief. Participants linked their praying to have more hope, feeling stronger, being more courageous, feeling able to forgive those who had hurt them. Many believed that through prayer, a higher power was able to intervene in their illness as well as life problems to provide help.

Regalia and Pelucchi (2014) argue that the self that has been surrendered to God is sometimes difficult to convince that they too have the power to reconstruct a new self. While some religious communities might insist that healing for HIV can happen only through prayer and not medication, no participants in this research believed that. Instead, participants believed that being spiritual helped the medical treatment to work. The closeness to God was helping the participants to heal and creating high prospect for forgiveness as the blame game was shifted to God's plan and design.

Spearman (2012) alluded to the fact that with time, the surviving HIV positive spouses start a process of self-identity reconstruction that includes conciliation, disclosing of HIV status and migration towards economic independence and forgiving the self of being HIV positive. This requires a great understanding of what it is and what it means to be HIV positive and Majola (2014) says self-identity reconstruction influenced individual behaviour through which the individual dialogues the self to acknowledge a radical shift in perspective and reorientation of personal behaviours to positive living. After realising that the HIV is there to stay and identifying reasons for living especially those that have children, the surviving HIV positive spouses had to focus to the future and reconciled with themselves in order to move on with their lives. This was a process that was directed towards moving from the perceived spoiled self to the reconstructed self. There are those who survive and move on without having accepted fully their situations and the correlation that exists between the morality and HIV acquisition makes the understanding of HIV a bit difficult for many people.

While the surviving HIV positive spouses confess that they have learnt a lot from life and that they take their medication, they still have unanswered questions about themselves and also about their late spouses. The late spouses have nothing to answer as of now and all answers, if they are to be found, should come from them, they are looking for answers from wrong places because the late spouses would never offer answers to their questions. The answers lie in them reconciling and forgiving themselves for what role they played in the coming of HIV and eventually the death of their spouses. However, the fact that they are taking their medication without failure is a step in the right direction towards healing and reconstruction of self-identity. For Mafana, attending the church organisations that deal with HIV issues is an added advantage towards reconciliation and forgiving especially that the organisations are offering the counselling services for free.

De Waal (2013) acknowledged that self-identity reconstruction emanated from the means and ways through which we managed and manipulated environmental variables such as stigma, economic dependence, and lack of knowledge. We see this through Sharon’s efforts to raise funds for furthering her education and taking her medication in combination with her spiritual life and, above all, making sure that her daughter is well catered for. Matunzeni shows the great zeal for recovery and moving on as she emphasises working hard to be economically

independent having brought up her sons to be independent. Whitehead (2014) says the experience of reconstructed identity is felt if all aspects that were present before the spoiled identity were achieved and we are seeing this with Derek as he gears up for remarrying when he has mourned his late wife. This posturing from Derek shows that he is moving towards a certain future where there are plans and preparations indicative of someone who has accepted his HIV positive status and ready to face the future.

### 6.6 Chapter Summary

Emerging from the discussion is that the self-identity reconstruction is affected by the past, present and the possible future behaviours. Self-identity track shows that there is a dialogue within an individual in evaluating the past self in comparison with the current state of self. The acceptability and denial of HIV positive status depends heavily on the past behaviours. I attempted to show that the self is a mental construct forming the content of human experience.

The surviving HIV positive spouses in their self-identity track are influenced by early life values, their marriage life, death of their partner, their HIV positive status, and stigma and discrimination on their journey to reconstruct a new self. It is very important for them (the surviving HIV positive spouses) to understand and navigate these factors in their self-conversations for a newly reconstructed self-identity to emerge. The significant others also play a key role in the reconstruction of a new self-identity as they provide a conducive environment for HIV positive status disclosure and support system that quickens recovery. It is important for the surviving HIV positive spouses to understand their past, current and possible future selves and to create spaces for dialogues within themselves as they (the surviving HIV positive spouses) review their past, current and possible future selves in the face of HIV positive status. The surviving HIV positive spouses finally start a process of self-identity reconstruction that includes conciliation, reconciliation, forgiveness and acceptability of HIV positive status. However, this requires a dialogical self that understands what it is and what it means to be HIV positive, thereby acknowledging a radical shift in perspective and orientation of personal behaviours to positive living. The next chapter will look at the conclusions drawn from these discussions, methodological shortcomings and recommendations made.

# CHAPTER SEVEN
# CONCLUSION

## 7.1 Introduction

This study was premised on exploring the nature of changes that take place in the surviving HIV positive spouses' explanatory of their self in relation to their acquired HIV positive status, and in relation to the role that forgiveness may play through the dialogical self in the self-identity reconstruction process. To achieve this aim, discussions were made in the previous chapter in view of the research questions and themes that emerged from the findings. This chapter will provide ways in which I draw conclusions in response to the set aim and research questions, state the methodological shortcomings and make recommendations.

This research sought to qualitatively track the self-identity reconstruction among the surviving HIV positive spouses and evaluate whether they would have forgiven themselves through self-conversations using the dialogical self theory. In the self-conversations, I found out that the life of a surviving HIV positive spouse was affected by a plethora of events happening in their environment such as life with HIV, relationship with significant others, view of past self and possible future self, and forgiveness as a way of moving on. There are surfeits of challenges that widows and widowers encounter following the death of their spouses from HIV related illnesses. Being HIV positive brings about life values shift, the shift in terms of what we eat, in terms of what we perceive, in terms of our significant others, our physiological physique, medication and our lifestyle. The diagnosis that brings HIV positive status results devastate the body reducing it to a 'spoiled self' that is looked down upon by the self under the self-hate of being damaged and feeling of being wasted. In this crushed self, there is a need to build a strong self-identity that will propel an individual to a better future. Self-identity was tracked through dialogical self theory propounded by Hermans (2003), which looks at what goes on in the inside and outside of the person.

The surviving HIV positive spouses seek to develop an understanding of the self in response to the acquired HIV positive status. Cohen and Sherman (2014) agree that individuals always search for evidence to know themselves better. Stanghor (2013) believes that when individuals know about themselves and have developed a positive self-concept they can modify and suit

their behaviour for a better future and hold self-conversations that can lead to knowledge based decisions that reduce cognitive dissonance. Knowledge gained of the self builds an individual's self-awareness. This current research found out that some participants often engaged in self-deceptions and positive illusions and this resulted in them failing to comprehend their HIV positive status as they kept blaming others. The blame game takes centre stage as surviving HIV positive spouses keep pushing the blame and searching for the source of HIV, and this creates a crisis between the actual self and the ideal self. In line with Pryer and Reeder (2015), the public self is highly dependent on significant others when the surviving HIV positive spouses had difficulty disclosing their statuses as seen in this current research.

Self-loathing and self-blame shown by some participants led to self-hate exhibited by Mafana and Methembe and such behaviours impacted negatively on life enjoyment and quality of life. HIV was seen as an enemy of loyalty, honesty and commitment to the marital union by the participants of the current research. In line with Jangu et al. (2017) who observed that being infected with HIV when in a marital union can be explained as a transgression, an act of wrong-doing, this research found out that HIV infection was perceived as an immoral act by the research participants. Forgiveness was reached through self-conversations, self-talk and dialogical self often motivated by the desire to give oneself peace of mind and move on with life. The same was observed by Peterson and Van Tongeren (2016) that the decision to forgive is often followed after the observation of perverse influences of resentments on personal life. The greater good of the welfare of children played a greater role in the achievement of forgiveness.

The research concluded that life with HIV in self-identity reconstruction track was very difficult as it is still associated with stigma and discrimination. Significant others play an important role in their relationship with their HIV positive relatives as their supportive behaviours create confidence and high self-esteem, which are good ingredients for self-identity reconstruction. Being at peace with the past self is a good quality for giving hope for stability and preparation for a good future. The research further concluded that knowledge is power because those that are knowledgeable of HIV were quick to recover and reconstruct their self-identity, and embrace reconciliation and forgiveness as a way of moving on with their lives, to underscore that it is *'Better to know than not to know for the benefits are huge'.*

### 7.2 Methodological shortcomings

Interpretive Phenomenological Analysis (IPA) is concerned with the in-depth exploration of personal lived experience and with how people make sense of their experience; the type of research question suitable for an IPA study is likely to involve issues and experiences of considerable significance to the participants. It was at this level when participants tended to give more information than the questions demanded, negatively affecting the allocated time per participant. However, I tried in some cases to moderate the responses to keep the participants focused, but I did not want to interfere too much with their free responses.

Some of the participants were using the interviews as their psychotherapy sessions as they vented out all that they had bottled for years. I reminded the participants that the informed consent process and research interactions emphasise the voluntary nature of participation in the interviews and that they could revoke their involvement at any time without any consequences whatsoever. The first participant showed signs of venting out towards the end of the interview. I politely asked her whether she was still comfortable to continue with the interview and she felt that she was comfortable but I asked for her permission for us to stop. She agreed. I then asked her if she would like to say more about the topic to someone else and she agreed. We both (myself and the participant) settled for the local counsellor at the hospital who was on standby for an eventuality. The second participant showed signs of unresolved psychological issues half-way the interview. She agreed that she was being overwhelmed by the narration of her past and present experiences involving HIV issues and how the society had been treating her. We both agreed to stop the interview and I asked her if she was prepared to talk to the local counsellor about her unresolved psychological issues. She agreed and I accompanied her to the counsellor's office. After some hours the counsellor phoned me to come to her office. The counsellor informed me that the participant was willing to continue with the interview. I was uncomfortable with the idea of continuing with the interview and the counsellor could sense my uneasiness, and she suggested that the interview could continue the following day and both the participant and myself agreed. The following day we started with a meeting between me, the participant and the counsellor. The participant assured us that she was ready and prepared to complete the interview. The second interview went well to completion without any problems. As indicated in my reflexivity statement, I went back to Manama Mission after two weeks to check on the two participants and I found them doing very well.

## 7.3 Recommendations

This study aimed at tracking the self-identity reconstruction by means of forgiveness through dialogical self theory of the surviving HIV positive spouses. The research concluded that life with HIV affects self-identity reconstruction negatively, that significant others play a pivotal role through their supportive behaviours in self-identity reconstruction and that knowledge and education on HIV could serve as good ingredient for reconciliation and forgiveness among the surviving HIV positive spouses. I wish to recommend that HIV education and the issue of stigma and discrimination be incorporated at all levels of our education system.

The current study was conducted among the surviving HIV positive spouses and the findings showed that the self-identity destruction begins right at the diagnosis, I, therefore, recommend future studies to explore the lived experiences of couples when both spouses are still alive and taking note of the influence of the past self on the decision made by the current self. I further recommend that forgiveness and reconciliation be made integral part of HIV recovery plan in HIV medication.

## 7.4 Chapter Summary

The chapter summarised the detailed discussion of the identified themes and drew conclusions in response to the research questions. Methodological shortcomings were identified and recommendations were made in response to the conclusions drawn. The conclusions showed that self-identity reconstruction for the surviving HIV positive spouses was a long journey that requires a lot of support from the significant others and the society at large. There is a need for the education system to introduce a well thought out and comprehensive curriculum that focuses on HIV related matters as lack of knowledge was found to be the key driver of stigma and discrimination. Finally, it is critical for forgiveness and reconciliation to be part of the central focus areas linked to HIV management.

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## List of Appendices

Ref. No: PERC-16032

UNISA university of south africa

Department of Psychology

**Ethical Clearance for M/D students: Research on human participants**

*The Ethics Committee of the Department of Psychology at Unisa has evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA and the Unisa Policy on Research Ethics.*

**Student Name:** Sibangilizwe Maphosa **Student no.** 36261653

**Supervisor:** Prof P Segalo **Affiliation:** Research and Graduate Studies, Unisa

**Title of project:**

Forgiveness through the dialogical self: A qualitative track of self-identity reconstruction among the surviving HIV positive spouses in Gwanda South Constituency

The proposal was evaluated for adherence to appropriate ethical standards as required by the Psychology Department of Unisa. Because of the sensitivity of the information being sought and the fact that the participants come from a vulnerable group, the application was approved by the Ethics Committee of the Department of Psychology on the understanding that –

- All ethical requirements regarding informed consent, the right to withdraw from the study, the protection of participants' privacy and confidentiality of the information should be made clear to the participants and adhered to, to the satisfaction of the supervisor;
- Clearance is to be obtained from the hospitals from which the participants are to be drawn, and all conditions and procedures regarding access to staff for research purposes that may be required by these institutions are to be met.
- If further counseling is required in some cases, the participants will be referred to appropriate counseling services.

*Signed:*

Papaikonomou

**Prof. M Papaikonomou**

*[For the Ethics Committee ]*

*[ Department of Psychology, Unisa*

*Date: 2016-09-22*

*The proposed research may now commence with the proviso that:*

1) *The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*
2) *Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Psychology Department Ethics Review Committee.*
3) *An amended application should be submitted if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*
4) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

***Please note that research where participants are drawn from Unisa staff, students or data bases requires permission from the Senate Research and Innovation Committee (SENRIC) before the research commences.***

UNISA university of south africa

**Prof Puleng Segalo (Associate Professor, Department of Psychology, UNISA)**

Tel: +27-12-4298292(w) Fax: +27 -12-4293414

Email: segalpj@unisa.ac.za Mobile: +27-73-0115372

This letter serves to confirm that Mr. Sibangilizwe Maphosa is currently registered (under my supervision) for his PhD in the Department of Psychology at the University of South Africa. His student number is (36261653). He worked on and successfully completed his research proposal recently (October 2016) and is currently in the preliminary stages of his dissertation.

Yours Sincerely

.....

Prof. P. Segalo

27 -10-2016

University of South Africa
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**Medical Research Council of Zimbabwe**
**Josiah Tongogara / Mazoe Street**
**P. O. Box CY 573**
**Causeway**
**Harare**

**APPROVAL**

**REF: MRCZ/A/2148** **3 April, 2017**

**Sibangilizwe Maphosa**
**UNISA**
Department of Psychology
P.O Box 392
Pretoria
**South Africa**

**RE:- Forgiveness Through The Dialogical Self: A Qualitative Track of Self-identity reconstruction among the surviving HIV-Positive Spouses in Gwanda South Constituency.**

Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review:-

1. Full Protocol
2. Research summary
3. Informed Consent forms (English and Ndebele)
4. Informed Consent forms – verbal reading (English and Ndebele)
5. In-depth Interview Guide(English and Ndebele)

- **APPROVAL NUMBER** **: MRCZ/A/2148**

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF MEETING** **: Normal review**
- **EFFECTIVE APPROVAL DATE** **: 03 April, 2017**
- **EXPIRATION DATE:-** **: 02 April, 2018**

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted three months before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw

**Other**

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

.....

**MRCZ SECRETARIAT**
**FOR CHAIRPERSON**
**MEDICAL RESEARCH COUNCIL OF ZIMBABWE**

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
2017 -04- 03
APPROVED
P.O. BOX CY 573 CAUSEWAY, HARARE

**PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH**

# MIDLANDS STATE UNIVERSITY

P. BAG 9055
Gweru.
Zimbabwe

Tel. (263) 54 260450/260464
260404/260331 260632/260596
FAX: (263) 54 260233


## FACULTY OF MEDICINE

19 December 2016

The Medical Research Council of Zimbabwe

**RE: COMMITMENT TO BE S. MAPHOSA`S LOCAL ADVISER**

This letter serves to confirm that Mr. Sibangilizwe Maphosa is currently registered for his PhD in the Department of Psychology at the University of South Africa. His student number is (36261653). He worked on and successfully completed his research proposal recently and is currently in the preliminary stages of his dissertation.

I, Dr. Julia Mutambara (PhD Psychology), undertake to be his local adviser in this project.

Attached is my contact details and CV.

Yours Sincerely,

**Dr Julia Mutambara**

**(Chairperson - Behavioural Sciences Department)**

MIDLANDS STATE UNIVERSITY
FACULTY OF MEDICINE
04 JAN 2017
PRIVATE BAG 9055
GWERU, ZIMBABWE
TEL: (263) 54 260450/260464

# RESEARCH STUDY

Conducted by **SIBANGILIZWE MAPHOSA** (36261653) of UNISA: Department of Psychology. 15 Clovely Crescent, Southdowns, Gweru, Zimbabwe.

Supervised by **Prof. Puleng. J. Segalo:** Head: Graduate Studies and Research, P. O. Box 392, Unisa, Pretoria, 0003: Email: segalpj@unisa.ac.za Phone: **+27124298292 or +27730115302**

## IF YOU ARE A WIDOW OR WIDOWER LIVING WITH HIV/AIDS:

- **Between ages of 21 and 50**
- **Should have been a widow or widower for a year or more**
- **Should have found your HIV status after marriage**
- **Should be able to endure interviews lasting up to an hour**

## YOU ARE INVITED TO VOLUNTEER IN THIS STUDY!!!!!!!!!!!

The purpose of this study is to unearth the feelings of the surviving HIV positive spouses as they travel the journey of self-identity reconstruction by means of forgiveness through the dialogical self.

## CONFIDENTIALITY IS MY FIRST PRIORITY!!!!!!!

I want to hear your story!! Make your voice heard!!!!!!

Participants will be selected from the Opportunistic Infection Clinic (O. I. C) at Manama Mission Hospital in Gwanda South Constituency.

I am hoping to interview at least ten participants that is 5 widows and 5 widowers.

For further information contact the local adviser: **Dr. Julia Mutambara:** Cell number: **0772937136**

**If you have questions about your rights as a research participant or feel you have not been treated fairly, please call Medical Research Council of Zimbabwe (MRCZ) on telephone (04) 791792 or (04) 791193 and Cell number 0784956128**

**ELCZ MANAMA MISSION HOSPITAL**
P.Bag 5845
GWANDA
TEL: (263) 0716563357
Email:manamamissionhospital@yahoo.com

27 October 2016

Medical Research Council of Zimbabwe
Harare

**RE:PERMISSION TO DO DATA COLLECTION ON PHD RESEARCH FOR SIBANGILIZIWE MAPHOSA.**

We have the authorised the above mentioned individual to collect data HIV/AIDS related issues for PhD research entitled "forgiveness through the dialogical self: a qualitative track of self-identity reconstruction among the surviving HIV positive spouses in Gwanda South Constituency."

Thank you.

Dr M. Hove
Medical Superintendent

MEDICAL SUPERINTENDENT
MANAMA MISSION HOSPITAL
27 OCT 2016
P. B. 5845, GWANDA
TEL: 0884- 23304 / 23276

**Appendix A**

**Participant Information and Informed Consent Form.**

Dear Participant.

My name is **Sibangilizwe Maphosa.** I am a PhD student at the University of South Africa (UNISA), College of Human Sciences. I am carrying out a research entitled: **Forgiveness through the dialogical self: A qualitative track of self-identity reconstruction among the surviving HIV positive spouses in Gwanda South Constituency.** I am interested in the self-identity reconstruction of the surviving HIV positive spouses.

You are invited to volunteer for this research study. This information is to help you to decide if you would like to participate. Before you agree to participate in the study you should fully understand what is involved. If you have any questions please do not hesitate to ask me to explain or elaborate on any statement. You should not agree to take part unless you are completely happy about all the procedures involved and unless you feel that you have a good understanding of what the study entails.

The purpose of this study is to unearth the feelings of the surviving HIV positive spouses as they travel the journey of life after losing their partners to death. More specifically its objectives are to:

1. Track the nature of changes that take place in the surviving HIV positive spouses' explanatory of their selves in relation to their acquired HIV positive status.

2. Track the nature of relationship that exist between the surviving HIV positive spouses with their significant others.

3. Track how the surviving HIV positive spouses compare their past selves with their current and possible future selves.

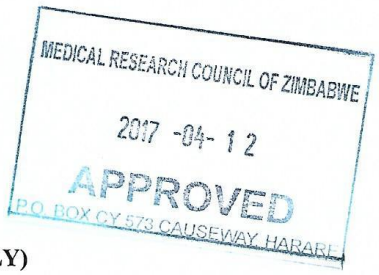
Please note that your participation in this study is entirely voluntary and you can refuse to participate or stop at any time without prejudice. You can also withdraw your consent at any time, before, during or at the end of the interview session. You may feel uncomfortable about answering some of the questions as sexual behaviors, HIV/AIDS and death are sensitive issues. If indeed you feel uncomfortable with answering a question, you may decline to respond.

The interview session will take place in private, either at your home or at the Hospital, the choice will be yours. All the interviews will be captured through audio-recording. I will then use the recorded information for further analysis. All information obtained will be strictly confidential and the only people who will have access to the recorded interviews will be myself, my supervisor and the examiners. Results of the study that may be reported in scientific journals will

I may at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient time to ask questions and declare myself prepared to participate in the study.

| | |
|---|---|
| …….. | ……. |
| Signature of Participant | Date |
| …….. | …….. |
| Signature of Researcher | Date |

8




**APPENDIX B**

**CONSENT TO PARTICIPATE IN RESEARCH (VERBALLY)**

You are being asked to participate in a research study. The research will be explained to you verbally.

My name is **Sibangilizwe Maphosa.** I am a PhD student at the University of South Africa (UNISA), College of Human Sciences. I am carrying out a research entitled: **Forgiveness through the dialogical self: A qualitative track of self-identity reconstruction among the surviving HIV positive spouses in Gwanda South Constituency.** I am interested in the self-identity reconstruction of the surviving HIV positive spouses.

You are invited to volunteer for this research study. This information is to help you to decide if you would like to participate. Before you agree to participate in the study you should fully understand what is involved. You should not agree to take part unless you are completely happy about all the procedures involved and unless you feel that you have a good understanding of what the study entails.

**PURPOSE**

You are being asked to participate in a research study of a track of self-identity reconstruction among the surviving HIV positive spouses. The purpose of this study is to unearth the feelings of the surviving HIV positive spouses as they travel the journey of life after losing their partners to death. More specifically its objectives are:

- Track the nature of changes that take place in the surviving HIV positive spouses' explanatory of their selves in relation to their acquired HIV positive status.
- Track the nature of relationship that exist between the surviving HIV positive spouses with their significant others.
- Track how the surviving HIV positive spouses compare their past selves with their current and possible future selves.

You were selected as a possible participant in this study because you meet the prescribed characteristics of the research participants.

**PROCEDURES AND DURATION**

If you decide to participate, you will undergo three interviews. All the interviews will be audio taped. Individual interviews will be conducted in 3 phases per participant. Each interview will last approximately an hour. However, you will be free to stop if you feel that you are tired or that you cannot continue. If you stay far from the Hospital, you can make a choice to come to the

Hospital or to be interviewed at your home. If you choose to come to the Hospital you will be given transport fare, breakfast and lunch per your interview session. In the interviews will take about 3 to 4 weeks that is one interview per week.

In the first interview, I will try to establish the context of your experience before marriage. This I will refer to it as "Life before marriage." The second interview will be in two parts: Part one will look into marriage before the discovery of HIV status; Part two will look into marriage life with HIV positive status up to the death of your spouse. The third and final interview will also have two parts. Part one will look into the life after the death of the spouse; Part two will look into the current and possible future life. In using the structure of the three-tier-interview method, with each interview having its own distinct purpose, I am hoping that the context, the details and the meanings will emerge in the interviews.

**BENEFITS AND/OR COMPENSATION**

I hope the study will be of great benefit to the counselors as they will be informed of what happens to the surviving HIV positive spouses in their journey to reconstruct their new selves. This will sharpen the skills of counseling for the counselors and help those affected. However, I do not guarantee or promise that you personally will receive any benefits direct from this study. If you opt to travel to the Hospital, you will be offer transport fare, breakfast and lunch.

**CONFIDENTIALITY ASSURANCES**

You are advised that participation will be voluntary and there are no monetary benefits for participating in this research. A number of measures will be put in place to ensure non-maleficence and protect your autonomy. Thus no harm will be inflicted on you directly or indirectly, intentionally or unintentionally as a result of this research. Interview transcripts and audio recorders will be kept at a secure location under lock and key by the arrangement with the supervisor and the local adviser. You will use a fictitious name that is pseudo name to protect your identity and your pseudo name will be converted into a code name in the final report. Interviews will be conducted in private and there will be no video recording to protect your identity.

**DISPOSAL OF CONFIDENTIAL MATERIAL**

Data and documents collected in connection with this study will be stored on a password computer in the supervisor's office at UNISA premises for 3 years following completion of the study. All audio recordings will be deleted upon transcription. All transcribed files, consent forms, and any other data relating to the study will be destroyed three years after completion of the study. Confidentiality of responses will be maintained by means of assigning numerical codes to each participant's transcribed responses.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with the OI Clinic, its personnel, and associated hospital, Manama Mission District Hospital. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.

I am aware that interviews will be audio recorded and that the results of the study will be anonymously processed into a study report.

If you agree to participate you will be given a signed copy of this document.

You may contact **Dr. Julia Mutambara** phone number **0772937136** any time you have questions about the research. You may contact **MRCZ** phone number **0784956128** if you have questions about your rights as a research participant.

Signing this document means that the research study, including the above information, has been described to you **ORALLY**, and that you voluntarily agree to participate.

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Signature of Participant (Thumb print) Date

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Signature Witness Date

**APPENDIX B**

**ISIVUMELWANO NGOPHATHEKAYO ESICHWAYISISWENI (NGOKUKHULUMA)**

**KOPHATHEKAYO:** Uyacelwa ukuba uphatheke njalo konke okuphathelane lesichwayisiso uzakuchasiselwa ngomlomo.

Igama lami ngu**Sibangilizwe Maphosa**, ngiqhuba izifundo zePhD eyunivesithi yaseSouth Africa eUNISA. Ngiqhuba isichwayisiso ngesihloko esithi **Forgiveness through the dialogical self: A qualitative track of self identity reconstruction among the surviving HIV positive spouses in Gwanda south consituency (uxolo oluza ngokukhulumisana lemibilini yakho: ukulandisa ngokuzithola lokuzibumba kakutsha kwalabo abatshiywa ngomkabo ngenxa yengciwane lengculaza esiqintini seGwanda.)** Ngithakazelela imvuselelo yokuzazi ngcono kulabo abalegcikwane lengculaza abatshiywa ngomkabo.

Uyanxuswa ukuba uphatheke kulesisichwayisiso. Ulwazi lolu lujonge ukukuncedisa ukuba ucabangisise ukuba uyafuna yini ukuphatheka. Ungakavumi kumele uqale uzwisise ukuthi lesi isichwayisiso simumetheni. Ungavumi ukuphatheka ngaphandle kokuba ulesifiso njalo uzwisisa ukuba vele lesisichwayisiso siquketheni.

**Injongo nhloso**

Uyacelwa ukuba uphatheke esichwayisisweni esilanda ukuzazi ngokuzibumba kakutsha kwalabo abatshiywa ngomkabo ngenxa yegciwane lengculaza. Injongo yale indingisiso iyikuveza imizwa yalabo abatshiywa ngomkabo besaphila emhlabeni emva kokubhujelwa ngomkabo. Injongo yalesi isichwayisiso iyi:

- Ukulonda inguquko ezibakhona kulabo abaseleyo, bezichaza bedlelanisa lokuthola igciwane lengculaza.

- Ukulonda ubudlelwano obukhona phakathi kwalabo abatshiywa ngomkabo lalabo ababatshiyayo.
- Ukulonda ukuba labo abatshiywa ngomkabo baqathanisa njani impilo abayiphila khathesi laleyo ababeyiphila kanye lokungenzeka kwelizayo.

Ukhethiwe ukuba ungaba ngomunye walabo abazaphatheka kulesi isichwayisiso ngoba uphelelisa indingeko zalabo abangaphatheka esichwayisisweni.

**INGQUBO LESIKHATHI ESIZATHATHWA**

Nxa uzaphatheka, uzabuzwa okwamahlandla amathathu. Ingxoxo mibuzo zizathatshwa zigcinwe kusigxingimazwi. Ingxoxo mbuzo yophathekayo izaqhutshwa okwamahlandla amathathu ngomuntu ngomuntu. Ingxoxo mibuzo yinye ngayinye izathatha ihola lonke. Uvunyelwe ukuma ukuphendula nxa usussizwa usukhathele kumbe ungasafuni ukuqhubeka. Nxa uhlala khatshana lesibhedlela uvunyelwe ukukhetha ukuza esibhedlela uzobuzwa kumbe ukulandwa uzobuzelwa emzini wakho. Ungakhetha ukuza esibhedlela uzaphiwa imali yenqola yomlilo, ukudla kwekuseni kanye lokwemini kusiya ngesikhathi ozabuzwa ngaso. Ingxoxo mibuzo le izathatha amaviki amathathu kusiya kwamane ngoba ingxoxo mibuzo yinye ngayinye izathatha iviki elilodwa.

Engxoxweni mibuzo yokuqala, umchwayisisi uzadingisisa inkambiso yakho ungakatshadi, 'impilo ungakatshadi'. Ihlandla lesibili lizaqunywa kabili: elakuqala lizagxila emtshadweni lingakakwazi ngesimo senu; ihlandla lesibili lizakhangela impilo emtshadweni wenu emva kokwazi ngesimo senu selilegciwane lengculaza. Ihlandla lesithathu njalo lingelokucina lizaqunywa kabili. Ingxenye yakuqala izakhangela impilo emva kokutshiywa ngumkakho. Ingxenye yesibili zakhangela okwenzeka khathesi lalokho okukhangelelwe ukwenzeka kwelizayo.

Ngokusebenzisa ingxoxo mibuzo equnywe kathathu njalo idinga ulwazi olwehlukeneyo ngehlandla linye ngalinye, umchwayisisi ukhangelele ukuthi umumo, ulwazi olujulileyo kanye lengcazelo ezithile zizavela.

**UNCEDO LWESICHWAYISISO**

Ngilethemba lokuthi isichwayisiso lesi sizanceda abeluleki ukuze babekwazi okwenzekayo kulabo abatshiywa ngomkabo ngenxa yegciwane lengculaza labo bezama ukuzakha kakutsha. Lokhu kuzalola amakhono okweluleka kulabo abeluleka abatshiywa ngomkabo. Angethembisi ukuthi kukhona ozakuthola emva kokuqhutshwa kwalesi isischwayisiso. Nxa uzakhetha ukuxoxisana lomchwayisisi usesibhedlela uzaphiwa indleko zokuhamba kanye lokudla kwekuseni lemini.

**UKUGCINWA KOLWAZI OLUTHATSHIWEYO**

Uyacetshiswa ukuthi ukuphatheka kuya ngokufisa kwakho njalo akulambadalo. Kunengi okuzakwenziwa ukuze kugcinwe ulwazi oluthatshwe kuwe luvikelekile. Awusoze ulinyazwe okulenjongo ngenxa yalesi isichwayisiso. Igwaliba lengxoxo mibuzo kanye lezigxingi mazwi zizagcinwa endaweni efihlekileyo zikhiyelwe ngumqeqetshi oweluleka umchwayisisi. Uzasebenzisa igama elingayisilo lakho ukuze sikuvikele ungaziwa njalo lelobizo lizaphiwa inombolo ethile esichwayisisweni. Ingxoxo mibuzo izaqhutshelwa endaweni ecatshileyo njalo imifanekiso yakho ayisoze igcinwe esigxingini solwazi ukuzwe kuvikelwe wena.

**UKUGCINWA KOLWAZI OLUTHATSHIWEYO**

Ulwazi oluzathatshwa kanye lamagwaliba ozawancindezela azagcinwa endaweni efihlakeleyo kanye lasesigxingini solwazi elenombolo yokuwavula njalo azagcinwa ngumqeqetshi oweluleka umchwayisisi eUNISA okweminyaka emithathu emva

kokuqeda ukuchwayisisa. Izithaphamazwi zizesulwa wonke amazwi aziwathaphileyo nxa lawo mazwi eselotshwe phansi ngumchwayisisi. Lowo lalowo ophathekayo uzaphiwa inombolo eyiyo ezenza kungaziwa igama lakhe.

**UKUPHATHEKA ESICHWAYISISWENI**

Ukuphatheka kwakho kulesi isichwayisiso akuphoqelwa, uyazikhethela okufunayo. Ungakhetha ukungaphathek kulesi isichwayisiso, ubudlelwano bakho lesibhedlela akumelanga buguquke. Ungakhetha ukuphatheka, uvunyelwe ukwesula isivumelwano lokutshiya loba ngasiphi isikhathi.

Ngiyakwazi ukuthi ingxoxo mibuzo izathatshwa ngezithaphamazwi njalo impumela zalesi isichwayisiso zizahluzwa kungela kuveza igama lami.

Nxa uvuma ukuphatheka uzanikezwa ugwalo ozancindezela kulo.

Ungathinta **uDr Julia Mutambara** kunombolo zocingo ezithi 0772937136 loba ngasiphi isikhathi nxa uthe waba lemibuzo ngalesi isichwayisiso. Ungathinta **iMRCZ** kunombolo zocingo ezithi 0784956128 nxa ulemibuzo yamalungelo akho njengomuntu ophatheka kulesi isichwayisiso.

Ukuncindezela ugwalo lolu kutsho ukuthi uchasiselwe wazwisisa konke okuphathelane lesichwayisiso njalo uzaphatheka.

..... .....

Uncindezelo lophathekayo (isithupha) Usuku

..... .....

Uncindezelo lofakazayo Usuku

10.



**APPENDIX A**

**INFORMED CONSENT FORM**

Dear Participant

My name is **Sibangilizwe Maphosa.** I am a PhD student at the University of South Africa (UNISA), College of Human Sciences. I am carrying out a research entitled: **Forgiveness through the dialogical self: A qualitative track of self-identity reconstruction among the surviving HIV positive spouses in Gwanda South Constituency.** I am interested in the self-identity reconstruction of the surviving HIV positive spouses.

You are invited to volunteer for this research study. This information is to help you to decide if you would like to participate. Before you agree to participate in the study you should fully understand what is involved. You should not agree to take part unless you are completely happy about all the procedures involved and unless you feel that you have a good understanding of what the study entails.

**What you should know about this research study:**

- I am giving you this consent so that you may read about the purpose, risk, and benefits of this research study.
- The main goal of this research study is to gain knowledge that may assist in understanding and helping the surviving HIV positive spouses in their journey to reconstruct their selves.
- I cannot promise that this research will benefit you. As HIV/AIDS is a sensitive issue, this research can arouse some discomfort in your being.
- You have the right to refuse to take part, or agree to take part now and change your mind later.
- Whatever you decide, it will not affect your regular attendance to the Hospital.
- Please review this consent form carefully. Ask any questions before you make a decision.
- Your participation is voluntary.

**PURPOSE**

You are being asked to participate in a research study of a track of self-identity reconstruction among the surviving HIV positive spouses. The purpose of this study is to unearth the feelings of the surviving HIV positive spouses as they travel the journey of life after losing their partners to death. More specifically its objectives are:

- Track the nature of changes that take place in the surviving HIV positive spouses' explanatory of their selves in relation to their acquired HIV positive status.

- Track the nature of relationship that exist between the surviving HIV positive spouses with their significant others.
- Track how the surviving HIV positive spouses compare their past selves with their current and possible future selves.

You were selected as a possible participant in this study because you meet the prescribed characteristics of the research participants. The following criteria determine the suitability for participation in the study:

- Widows or widowers between the ages of 21 and 50.
- Being an HIV positive widow or widower.
- Should have been a widow or widower for a year or more.
- Should have found their HIV status after marriage.
- Should be able to endure interviews lasting up to an hour.

The study is premised to have approximately 5 widows and 5 widowers giving a total of 10 participants all based in Zimbabwe.

**PROCEDURES AND DURATION**

If you decide to participate, you will undergo an interview with three parts. All the interview parts will be audio taped. Each interview will last approximately an hour. However, you will be free to stop if you feel that you are tired or that you cannot continue. If you stay far from the Hospital, you can make a choice to come to the Hospital or to be interviewed at your home. If you choose to come to the Hospital you will be given transport fare, breakfast and lunch.

In the first part, I will try to establish the context of your experience before marriage. This I will refer to it as "Life before marriage." The second part will be in two sections: Section one will look into marriage before the discovery of HIV status; Section two will look into marriage life with HIV positive status up to the death of your spouse. The third and final part will also have section parts. Section one will look into the life after the death of the spouse; Section two will look into the current and possible future life. In using the structure of the three-tier-interview-parts method, with each part having its own distinct purpose, I am hoping that the context, the details and the meanings will emerge in the interviews.

**RISKS AND DISCOMFORTS**

You will be interviewed in private at the Hospital or at home, depending on your choice, to avoid being labeled and stigmatized as such. If during the interview session you develop some discomfort, the session will be stopped immediately and if so wish, you can withdraw totally from the research without any negative consequences. If you feel that your discomforts arouse as a result of painful memories, I would refer you to the trained counselors that work with HIV

positive people at the Hospital. These counselors will help you with psychological problems and interventions.

**BENEFITS AND/OR COMPENSATION**

I hope the study will be of great benefit to the counselors as they will be informed of what happens to the surviving HIV positive spouses in their journey to reconstruct their new selves. This will sharpen the skills of counseling for the counselors and help those affected. However, I do not guarantee or promise that you personally will receive any benefits direct from this study. If you opt to travel to the Hospital, you will be offer transport fare, breakfast and lunch.

**CONFIDENTIALITY ASSURANCES**

You are advised that participation will be voluntary and there are no monetary benefits for participating in this research. A number of measures will be put in place to ensure non-maleficence and protect your autonomy. Thus no harm will be inflicted on you directly or indirectly, intentionally or unintentionally as a result of this research. Interview transcripts and audio recorders will be kept at a secure location under lock and key by the arrangement with the supervisor and the local adviser. You will use a fictitious name that is pseudo name to protect your identity and your pseudo name will be converted into a code name in the final report. Interviews will be conducted in private and there will be no video recording to protect your identity.

**DISPOSAL OF CONFIDENTIAL MATERIAL**

Data and documents collected in connection with this study will be stored on a password computer in the supervisor's office at UNISA premises for 3 years following completion of the study. All audio recordings will be deleted upon transcription. All transcribed files, consent forms, and any other data relating to the study will be destroyed three years after completion of the study. Confidentiality of responses will be maintained by means of assigning numerical codes to each participant's transcribed responses.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with the OI Clinic, its personnel, and associated hospital, Manama Mission District Hospital. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.

**CONSENTING QUESTIONS**

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

**AUTHORIZATION**

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

| | |
|---|---|
| ---------- | ---------- |
| Name of Research Participant (please print) | Date |
| ---------- | ---------- |
| Signature of Participant | Time |
| ---------- | ---------- |
| Name of Staff Obtaining Consent (please print) | Date |
| ---------- | ---------- |
| Signature of Staff Obtaining Consent | Time |

**YOU WILL BE OFFERED A COPY OF THIS CONSENT FORM TO KEEP.**

If you have any questions concerning this study or consent form beyond those answered by the researcher, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the team, please feel free to contact the Medical Research Council of Zimbabwe (MRCZ) on telephone (04)791792 or (04)791193 and cell phone lines 0784956128. The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

**AUDIO RECORDING**

You are hereby requested to take part in a recorded (audio) one-on-one interview with me (researcher). A follow-up interview of 5-20 minutes a week following the initial interviews will be held to verify transcripts of the interview by you. If you do not consent to the audio recording of the interview, you may still participate in the study. The voice recording will later be transcribed. All audio recordings will be deleted upon transcription. All transcribed files will be destroyed three years after completion of the study. Confidentiality of responses will be maintained by means of assigning numerical codes to each participant's transcribed responses.

**STATEMENT OF CONSENT TO BE AUDIOTAPED**

I understand that audio recordings will be taken during the study. If you consent tick Yes and if you do not consent tick No in the following statement:

- I agree to **being audio recorded** **Yes [ ]** **No [ ]**

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Name of Participant (please print) Date

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Signature of Participant Time

**APPENDIX B**

**CONSENT TO PARTICIPATE IN RESEARCH (VERBALLY)**

You are being asked to participate in a research study. The research will be explained to you verbally.

My name is **Sibangilizwe Maphosa.** I am a PhD student at the University of South Africa (UNISA), College of Human Sciences. I am carrying out a research entitled: **Forgiveness through the dialogical self: A qualitative track of self-identity reconstruction among the surviving HIV positive spouses in Gwanda South Constituency.** I am interested in the self-identity reconstruction of the surviving HIV positive spouses.

You are invited to volunteer for this research study. This information is to help you to decide if you would like to participate. Before you agree to participate in the study you should fully understand what is involved. You should not agree to take part unless you are completely happy about all the procedures involved and unless you feel that you have a good understanding of what the study entails.

**PURPOSE**

You are being asked to participate in a research study of a track of self-identity reconstruction among the surviving HIV positive spouses. The purpose of this study is to unearth the feelings of the surviving HIV positive spouses as they travel the journey of life after losing their partners to death. More specifically its objectives are:

- Track the nature of changes that take place in the surviving HIV positive spouses' explanatory of their selves in relation to their acquired HIV positive status.
- Track the nature of relationship that exist between the surviving HIV positive spouses with their significant others.
- Track how the surviving HIV positive spouses compare their past selves with their current and possible future selves.

You were selected as a possible participant in this study because you meet the prescribed characteristics of the research participants.

**PROCEDURES AND DURATION**

If you decide to participate, you will undergo three interview-parts. All the interview-parts will be audio taped. Each interview will last approximately an hour. However, you will be free to stop if you feel that you are tired or that you cannot continue. If you stay far from the Hospital, you can make a choice to come to the Hospital or to be interviewed at your home. If you choose to come to the Hospital you will be given transport fare, breakfast and lunch.

In the first interview-part, I will try to establish the context of your experience before marriage. This I will refer to it as "Life before marriage." The second interview-part will be in two Sections: Section one will look into marriage before the discovery of HIV status; Section two will look into marriage life with HIV positive status up to the death of your spouse. The third and final interview-part will also have two Sections. Section one will look into the life after the death of the spouse; Section two will look into the current and possible future life. In using the structure of the three-tier-interview-parts method, with each interview-part having its own distinct purpose, I am hoping that the context, the details and the meanings will emerge in the interviews.

**BENEFITS AND/OR COMPENSATION**

I hope the study will be of great benefit to the counselors as they will be informed of what happens to the surviving HIV positive spouses in their journey to reconstruct their new selves. This will sharpen the skills of counseling for the counselors and help those affected. However, I do not guarantee or promise that you personally will receive any benefits direct from this study. If you opt to travel to the Hospital, you will be offer transport fare, breakfast and lunch.

**CONFIDENTIALITY ASSURANCES**

You are advised that participation will be voluntary and there are no monetary benefits for participating in this research. A number of measures will be put in place to ensure non-maleficence and protect your autonomy. Thus no harm will be inflicted on you directly or indirectly, intentionally or unintentionally as a result of this research. Interview transcripts and audio recorders will be kept at a secure location under lock and key by the arrangement with the supervisor and the local adviser. You will use a fictitious name that is pseudo name to protect your identity and your pseudo name will be converted into a code name in the final report. Interviews will be conducted in private and there will be no video recording to protect your identity.

**DISPOSAL OF CONFIDENTIAL MATERIAL**

Data and documents collected in connection with this study will be stored on a password computer in the supervisor's office at UNISA premises for 3 years following completion of the study. All audio recordings will be deleted upon transcription. All transcribed files, consent forms, and any other data relating to the study will be destroyed three years after completion of the study. Confidentiality of responses will be maintained by means of assigning numerical codes to each participant's transcribed responses.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with the OI Clinic, its personnel, and associated hospital, Manama Mission District Hospital. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.

I am aware that interviews will be audio recorded and that the results of the study will be anonymously processed into a study report.

If you agree to participate you will be given a signed copy of this document.

You may contact **Dr. Julia Mutambara** phone number **0772937136** any time you have questions about the research. You may contact **MRCZ** phone number **0784956128** if you have questions about your rights as a research participant.

Signing this document means that the research study, including the above information, has been described to you **ORALLY**, and that you voluntarily agree to participate.

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Signature of Participant (Thumb print) Date

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Signature Witness Date

**APPENDIX A**

**ULWAZI KANYE LESIVUMELWANO NGOPHATHEKAYO**

**KOPHATHEKAYO:**

Igama lami ngu**Sibangilizwe Maphosa**, ngiqhuba izifundo zePhD eyunivesithi yaseSouth Africa eUNISA. Ngiqhuba isichwayisiso ngesihloko esithi **Forgiveness through the dialogical self: A qualitative track of self identity reconstruction among the surviving HIV positive spouses in Gwanda south consituency (uxolo oluza ngokukhulumisana lemibilini yakho: ukulandisa ngokuzithola lokuzibumba kakutsha kwalabo abatshiywa ngomkabo ngenxa yengciwane lengculaza esiqintini seGwanda.)** Ngithakazelela imvuselelo yokuzazi ngcono kulabo abalegcikwane lengculaza abatshiywa ngomkabo.

Uyanxuswa ukuba uphatheke kulesisichwayisiso. Ulwazi lolu lujonge ukukuncedisa ukuba ucabangisise ukuba uyafuna yini ukuphatheka. Ungakavumi kumele uqale uzwisise ukuthi lesi isichwayisiso simumetheni. Ungavumi ukuphatheka ngaphandle kokuba ulesifiso njalo uzwisisa ukuba vele lesisichwayisiso siquketheni.

**Okumele ubekwazi ngalesi isichwayisiso:**

- Ngikupha lesisivumelwano ukuze ubale uzwisise injongo, okungavela kanye lempumela ezinhle zalesi isichwayisiso.
- Injongo emqoka yalesi isichwayisiso iyikuthola ulwazi olungaphathisa ekuzwisiseni lasekuncedeni labo abatshiywa ngomkabo ngenxa yegciwane lengculaza ukuze bazibumbe kakutsha.
- Angingeke ngithembise ukuthi isichwayisiso lesi sizaba lusizo kuwe. Ngenxa yokuthi iHIV/AIDs ithinta kakhulu imizwa yabanengi, isichwayisiso lesi singenza uzizwe ungasaphathekanga kuhle

- Ulelungelo lokwala ukuphatheka kumbe ukuphatheka okwakhathesi uphinde utshintshe ingqondo kwelizayo
- Konke okucabangileyo akumelanga kuguqule indlela yakho yokuvakatshela emtholampilo
- Hlolisisa isivumelwano lesi. Ubuze imibuzo ungakathathi isinqumo.
- Ukuphatheka kwakho kuya ngokufisa kwakho.

**Injongo nhloso**

Uyacelwa ukuba uphatheke esichwayisisweni esilanda ukuzazi ngokuzibumba kakutsha kwalabo abatshiywa ngomkabo ngenxa yegciwane lengculaza. Injongo yale indingisiso iyikuveza imizwa yalabo abatshiywa ngomkabo besaphila emhlabeni emva kokubhujelwa ngomkabo. Injongo yalesi isichwayisiso iyi:

- Ukulonda inguquko ezibakhona kulabo abaseleyo, bezichaza bedlelanisa lokuthola igciwane lengculaza.
- Ukulonda ubudlelwano obukhona phakathi kwalabo abatshiywa ngomkabo lalabo ababatshiyayo.
- Ukulonda ukuba labo abatshiywa ngomkabo baqathanisa njani impilo abayiphila khathesi laleyo ababeyiphila kanye lokungenzeka kwelizayo.

Ukhethiwe ukuba ungaba ngomunye walabo abazaphatheka kulesi isichwayisiso ngoba uphelelisa indingeko zalabo abangaphatheka esichwayisisweni. Okulandelayo kuveza ukuthi ovunyelwe ukuphatheka eyisimo bani:

- Abafelokazi labafelwa abaleminyaka ephakathi kwengamatshumi amabili alengxenye (21) lamatshumi amahlanu (50).
- Umfelokazi/ umfelwa ophila legciwane lengculaza.

- Kumele ube ungumfelokazi/ umfelwa oselomnyaka kumbe iminyaka eminengi.
- Kumele ube uthole igciwane lengculaza emva kokutshada.
- Kumele wenelise ukumelana lemibuzo ezathatha ihola.

Lesi isichwayisiso kumele sibe labafelokazi abahlanu labafelwa abahlanu. Behlangene bonke abaphathekayo balitshumi njalo bahlala eZimbabwe.

**INGQUBO LESIKHATHI ESIZATHATHWA**

Nxa uzaphatheka, uzabuzwa okwamahlandla amathathu. Ingxoxo mibuzo zizathatshwa zigcinwe kusigxingimazwi. Ingxoxo mbuzo yophathekayo izaqhutshwa okwamahlandla amathathu ngomuntu ngomuntu. Ingxoxo mibuzo yinye ngayinye izathatha ihola lonke. Uvunyelwe ukuma ukuphendula nxa usussizwa usukhathele kumbe ungasafuni ukuqhubeka. Nxa uhlala khatshana lesibhedlela uvunyelwe ukukhetha ukuza esibhedlela uzobuzwa kumbe ukulandwa uzobuzelwa emzini wakho. Ungakhetha ukuza esibhedlela uzaphiwa imali yenqola yomlilo, ukudla kwekuseni kanye lokwemini kusiya ngesikhathi ozabuzwa ngaso. Ingxoxo mibuzo le izathatha amaviki amathathu kusiya kwamane ngoba ingxoxo mibuzo yinye ngayinye izathatha iviki elilodwa.

Engxoxweni mibuzo yokuqala, umchwayisisi uzadingisisa inkambiso yakho ungakatshadi, 'impilo ungakatshadi'. Ihlandla lesibili lizaqunywa kabili: elakuqala lizagxila emtshadweni lingakakwazi ngesimo senu; ihlandla lesibili lizakhangela impilo emtshadweni wenu emva kokwazi ngesimo senu selilegciwane lengculaza. Ihlandla lesithathu njalo lingelokucina lizaqunywa kabili. Ingxenye yakuqala izakhangela impilo emva kokutshiywa ngumkakho. Ingxenye yesibili zakhangela okwenzeka khathesi lalokho okukhangelelwe ukwenzeka kwelizayo.

Ngokusebenzisa ingxoxo mibuzo equnywe kathathu njalo idinga ulwazi olwehlukeneyo ngehlandla linye ngalinye, umchwayisisi ukhangelele ukuthi umumo, ulwazi olujulileyo kanye lengcazelo ezithile zizavela.

**OKUNGAVELA LOKUNGAKUPHATHA KUBI**

Uzabuzwa endaweni esithekileyo esibhedlela kumbe ngekhaya kusiya ngokuthi wena ufunani ukuze senqabele ukubizwa ngamagama athile lokubandlululwa. Nxa ingxoxo mibuzo iqhutshwa, uvunyelwe ukumisa ingqubo yayo nxa ungasaphathekanga kuhle kumbe usudiniwe ungasafisi ukuphatheka. Nxa usizwa ukuthi ukungaphatheki kwakho kuhle kuvusa imicabango ebuhlungu lenhlungu ezinengi, uzanikwa umeluleki oqeqetshele ukukhuluma labantu abaphila legciwane lengculaza esibhedlela. Abeluleki bazakuncedisa ngenhlupho olazo kanye lalokho okungenqabela lezonhlungu.

**UNCEDO LWESICHWAYISISO**

Ngilethemba lokuthi isichwayisiso lesi sizanceda abeluleki ukuze babekwazi okwenzekayo kulabo abatshiywa ngomkabo ngenxa yegciwane lengculaza labo bezama ukuzakha kakutsha. Lokhu kuzalola amakhono okweluleka kulabo abeluleka abatshiywa ngomkabo. Angethembisi ukuthi kukhona ozakuthola emva kokuqhutshwa kwalesi isischwayisiso. Nxa uzakhetha ukuxoxisana lomchwayisisi usesibhedlela uzaphiwa indleko zokuhamba kanye lokudla kwekuseni lemini.

**UKUGCINWA KOLWAZI OLUTHATSHIWEYO**

Uyacetshiswa ukuthi ukuphatheka kuya ngokufisa kwakho njalo akulambadalo. Kunengi okuzakwenziwa ukuze kugcinwe ulwazi oluthatshwe kuwe luvikelekile. Awusoze ulinyazwe okulenjongo ngenxa yalesi isichwayisiso. Igwaliba lengxoxo

mibuzo kanye lezigxingi mazwi zizagcinwa endaweni efihlekileyo zikhiyelwe ngumqeqetshi oweluleka umchwayisisi. Uzasebenzisa igama elingayisilo lakho ukuze sikuvikele ungaziwa njalo lelobizo lizaphiwa inombolo ethile esichwayisisweni. Ingxoxo mibuzo izaqhutshelwa endaweni ecatshileyo njalo imifanekiso yakho ayisoze igcinwe esigxingini solwazi ukuzwe kuvikelwe wena.

**UKUPHATHEKA ESICHWAYISISWENI**

Ukuphatheka kwakho kulesi isichwayisiso akuphoqelwa, uyazikhethela okufunayo. Ungakhetha ukungaphathek kulesi isichwayisiso, ubudlelwano bakho lesibhedlela akumelanga buguquke. Ungakhetha ukuphatheka, uvunyelwe ukwesula isivumelwano lokutshiya loba ngasiphi isikhathi.

**IMIBUZO**

Uvunyelwe ukubuza loba yiyiphi imibuzo ephathelane lalindingisiso ungakancindezeli. Ungathatha isikhathi sakho eside ukuze ucabangisise.

**IMVUMO**

Lapha wenza isivumelwano sokuthi uyaphatheka loba awufisi ukuphatheka kulesi isichwayisiso. Uncindezelo lwakho luveza ukuthi ubalile wazwisisa konke okuqukethwe yilolugwalo, ubuzile yonke imibuzo waphendulwa ngendlela ekusuthisayo njalo usuzimisele ukuphatheka kulesi isichwayisiso.

..... .....

Ibizo lophathekayo Usuku

..... .....

Uncindezelo lophathekayo Isikhathi

..... .....

Ibizo labadinga isivumelwano Usuku

..... .....

Uncindezelo lwabadinga isivumelwano Isikhathi

**UZANIKEZWA LOLUGWALO OZALUGCINA**

Nxa ulemibuzo ephathelane lalesi isichwayisiso logwalo lolu engaphezulu kwaleyo oyibuzileyo wayiphendulwa ngumchwayisisi, imibuzo mayelana lesichwayisiso, amalungelo akho njengomuntu ophathekayo kumbe inhlungu ezidalwa yisichwayisiso, ukuzwa ungaphathekanga ngendlela efaneleyo njalo ufisa ukuveza ukuba awuphathwanga kuhle, thinta inombolo zocingo ezilandelayo **Medical Research Council of Zimbabwe (MRCZ)** (04)7911792 kumbe (04)7911793 loba ezikamakhalekhukhwini 0784956128. Laba batholakala eNational Institute of Health Research okuhlangana khona uJosiah tongogara loMazowe Avenue eHarare.

**UKUTHATSHWA KWAMAZWI**

Uyacelwa ukuba uphatheke engxoxweni mibuzo lomchwayisisi ezabe ithapha amazwi akho. Kuzaba lengxoxo mibuzo elandelela eyokuqala okwemizuzu emihlanu kusiya kwengamatshumi amabili (5-20) ngeviki ukuze kuhlolisiswe lokho osekulotshwe phansi ngawe. Nxa ungavumelani lamazwi ayabe eselotshiweyo, uvunyelwe ukuthi uphatheke njalo. Amazwi athatshiweyo azaguqulelwa ekulotshweni phansi. Nxa eselotshiwe, izithaphamazwi zizasulwa amazwi akho. Okulotshwe phansi lakho kuzatshiswa emva kweminyaka emithathu isischwayisiso siqhutshiwe. Ukugcina ibizo lakho lingaziwa muntu kuzahlonyiswa yikusebenzisa inombolo kulowo lalowo ozaphatheka.

**IMVUMO YOKUTHAPHA AMAZWI**

Ngiyazwisisa ukuthi amazwi ami azathatshwa ngesikhathi isichwayisiso siqhutshwa.

Nxa uvuma uzathwebula kuYebo loba kuHatshi nxa usala.

- Ngiyavuma ukuthi amazwi ami athatshwe **Yebo..... [ ] Hatshi..... [ ]**

..... .....

Ibizo lophathekayo Usuku

..... .....

Uncindezelo lophathekayo Isikhathi

12.

**Appendix B In-depth Interview Guide**

**PART 1: Life before marriage.**

1. Age ……..

2. Highest educational qualification ……

3. Type of school attended eg rural, urban, day etc

4. Type of family eg Intact

5. Religion ……..

6. Values about marriage ……

7. Values about sexual relationships

8. Dating history

9. Knowledge of HIV/AIDS

10. Expectations in a marriage

11. Type of a person before marriage

12. Guiding philosophy before marriage

13. Support system before marriage

-Peers, parents, siblings, teachers, workmates, etc

**PART 2:**

**SECTION: one: Marriage before discovery of HIV status.**

1. Age at marriage ……

2. Type of marriage eg traditional, white wedding etc

3. Accommodation, stayed with parents, own house, etc

4. Children eg how many, their ages, etc

5. History of illness in the marriage

6. General relationship in the marriage, husband/wife

7. Sexual life in marriage, eg cheating, use of contraceptives, trust issues

8. Views and thoughts on HIV/AIDS in marriage

9. Any history of HIV/AIDS testing

**SECTION two: Marriage life with HIV positive status.**

1. Who was the first to be tested? Approximately how long did it take to disclose?

2. How did you react to your status?

3. How did your spouse react?

4. What did you change both after discovery?

5. How was your relationship thereafter?

6. How did your status affect your sexual life?

7. How did you disclose to the significant others?

8. How did the significant others react to your being positive?

9. How did stigma and discrimination affect your lives?

10. Who was suspected to have brought the virus home? Why? How?

11. How difficult or easy was it to stay with your partner during the illness?

12. For how long was your partner ill? How was it to take care of your partner?

13. How was your support system during this period?

14. When your partner finally died where you there? How did you feel then?

15. What was always in your mind during this period?

16. What were your most regrets during this period?

**PART 3:**

**SECTION one: Life after the death of the partner:**

1. When did your partner die? Any memories?

2. How did you feel when your partner died? Was it a relief?

3. How angry are you about this death?

4. How guilty are you about this death?

5. How has been your support system after this death?

6. How is your view or relationship with your deceased partner as of now?

7. How has been your relationship with your significant others since death?

8. What are your views on stigma and discrimination towards HIV positive people?

9. What has been your strength up to now?

10. Any regrets as of now?

**SECTION two: Current and possible future life:**

1. How is it to be HIV positive?

2. Any experiences that you can share as lessons from this situation?

3. Any considerations of re-marrying? Why? How?

4. Do you think you have moved on? Explain your response further.

5. How are you coping with medication?

6. Any involvement in HIV/AIDS organizations? How?

7. What are you doing for your future? Studies? Investments?

8. Do you discuss HIV/AIDS issues with your children? How?

9. What is your understanding of HIV/AIDS? Do you think your situation has helped you understand better?

10. If you look back what would you have changed in your past life?

13.

**APPENDIX B (NDEBELE LANGUAGE)**

**INGXOXOMBUZO EJULAYO**

INGXOXOMBUZO YAKUQALA: IMPILO UNGAKATSHADI

1. Uleminyaka emingaki.....
2. Izinga lemfundo okulo.....
3. Wafunda kusiphi isikolo? (esekhaya, esedolobheni)
4. Usuka emulini enjani?
5. Uyakhonza ?
6. Umtshado uyawukhabitha na?
7. Uyabukhwabitha ubudlelwano besilisa lesifazane na?
8. Imbalo yakho yokuhlangana labesilisa lixoxa imi njani?
9. Ulwazi ngegcikwane lengculaza (HIV/AIDS)
10. Ukhangeleleni nxa usuthethwe?
11. Ubungumuntu onjani ungakathathi/wa?
12. Ubufuqwa yini ungakatshadi?
13. Ubukhuselelwa ngobani ungakatshadi (ngabangane, ngabazali, yizihlobo, ngosebenza labo)

**INGXOXOMBUZO YESIBILI:**

**Ingxenye yakuqala: umtshado ungakananzeleli ukuthi sulegcikwane.**

1. Uleminyaka emingaki utshadile.....
2. Ukuwuphi umhlobo womtshado....(owesintu, owesigqoko esimhlophe)
3. Uhlala kowakho umuzi kumbe uhlala labazali?
4. Ulabantwana abangaki? Baleminyaka emingaki?
5. Imbali yokugula kulo umtshado.
6. Liphilisana njani lomkakho?

7. Ukuziphatha kwezocansi lomkakho, (liziphethe, lisebenziswa okokuvikela, liyethembana).
8. Umibono lokucabangayo ngengcikwane lengculaza emtshadweni.
9. kulembali yokuhlolelwa igcikwane lengculaza (HIV/AIDS).

**Ingxenye yesibili: ukuphila lengculaza emtshadweni**

1. Ngubani owaqala ukuhlolwa? Kwathatha isikhathi esingakanani ukuze wazise omunye.
2. Waziphatha njani emva kokwazi ngesimo sakho?
3. Umkakho waphatheka njani ngesimo sakho?
4. Laguqulani emva kokwazi ngesimo senu?
5. Ubudlelwano benu baqhubeka bunjani?
6. Isimo senu saguqula njani ukuziphatha kwenu kwezocansi?
7. Wababikela njani abangane lezihlobo ngesimo sakho?
8. Zaphatheka njani izihlobo zakho usuzibikele?
9. Ukuhlengwa lokungemukelwa ngabantu kwaliphatha njani?
10. Ngubani owayecatshangelwa ukuthi uze lengculaza egumeni? Kungani? Njani?
11. Kwakulula kumbe kunzima kanganani ukuhlala lomkakho egula?
12. Wagula okwesikhathi esingakanani? Kwakunjani ukumonga?
13. Wawumncedisa ngani?
14. Umkakho esifa wawukhona? Wezwa njani?
15. Kuyini okwakusemicabangweni yakho ngalesosikhathi?
16. Wawuzisola kukuphi ngalesosikhathi?

**INGXOXOMBUZO YESITHATHU**

**Ingxenye yakuqala: Impilo ngemva kokufa komkakho**

1. Umkakho wabhubha nini? Kukhona osakukhumbula ngaye?

2. Wezwa njani umkakho aze afe? Wakwethula ijogwe elinzima?

3. Uzwa ubuhlungu obungakanani ngokufa kwakhe?

4. Ulesandla esingakanani ekufeni kwakhe?

5. Emveni kokufa kwakhe uphathiswa ngaluphi uhlobo?

6. Ubudlelwano bakho lomkakho owakutshiyayo bunjani okwakhathesi?

7. Ubudlelwano bakho lezihlobo eziseduzane bunjani?

8. Yiphi imibono ngegcikwane lengculaza olayo?

9. Kuyini obambelele kukho, okukuqinisayo?

10. Ulakho ukuzisola na?

**Ingxenye yesibili: Impilo yalamhla lakwelizayo:**

1. Kunjani ukuphila legcikwane lengculaza?

2. Inkambiso olayo ngokuphila legcikwane lengculaza ingabe ilezifundo bani?

3. Uzafuna ukubuya utshade? Kungani? Njani?

4. Ucabanga ukuthi osewadlula kukho awusakubuyeleli? Chasisa impendulo yakho.

5. Uphila njani ngoncedo oluthola esibhedlela (amaphilisi lokwelulekwa)?

6. Usuke waphatheka na enhlanganisweni zeHIV/AIDS? Njani?

7. Kuyini okwenzayo okuzaphathisa ikusasa lakho? Uyafunda? Kukhona okulondolozayo?

8. Uyaxoxa labantwabakho ngegcikwane leHIV/AIDS? Njani?

9. Uyizwisisa okunganani i- HIV/AIDS? Ucabanga ukuthi isimo okuso sikwenze wazwisisa ngcono ngegcikwane leHIV/AIDS?

10. Nxa ungakhangelisisa owadlula kukho, kuyini ongafisa ukuthi aluba uyakuguqula?